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Expert Patient Programme for Recently Diagnosed Patients With Chronic Open Angle Glaucoma (COAG)

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Declaration

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Abstract

Chronic Open Angle Glaucoma (COAG) refers to a chronic progressive condition that is characterised by damage to the optic nerve, resulting in peripheral visual loss that can progress to involve the fovea and central vision; subsequently causing blindness. COAG is reported to have a poor level of adherence to treatment due to its asymptomatic nature. In this study, a Glaucoma Expert Patient Programme (GEPP) demonstrated new ways of improving patients' experience and adherence to COAG treatment. The research has employed an Information-Motivation-Behavioural Skills Model to understand the association between knowledge, motivation and behavioural skills in an attempt to improve adherence amongst recently diagnosed patients. Patient participation was at the heart of every component of the study.

In this research, four Expert Patients were trained and supported to deliver an educational programme (termed the GEPP) to 25 recently diagnosed patients with COAG (Intervention Group) and then a comparison was made to 25 participants (Control Group) that were also recently diagnosed with COAG but did not receive the educational programme. Three pre and post educational programme validated questionnaires were used to measure patients' knowledge, satisfaction and adherence at baseline and then discern changes at 1 month and 6 months follow up to the GEPP intervention. Staff (N = 10), Expert Patient (N = 4), Intervention Group (N=10) and Control Group (N=10) semi-structured interviews were also conducted to obtain deeper insight into their experiences of engaging in the programme. Data analysis indicated IMPROVING AWARENESS was the main theme that emerged supported by three subthemes: knowledge, satisfaction and adherence. This research has taken the Patient-Patient relationship to a higher level. It is viewed that the Expert Patients' experience is crucial and valuable to improving the experience, knowledge and adherence of newly diagnosed patients with COAG.

The GEPP delineated in this study provided insight regarding individuals' life experiences of living with and managing chronic complex glaucoma. Implications for practice relate to the development of tailored educational programmes. This research contributed new knowledge to improving the adherence practices of glaucoma patients. It also demonstrated the value of Expert Patients' experience and their contribution to assisting newly diagnosed patients in self-managing their COAG.

CHAPTER ONE

Introduction

The research explicated in this thesis was conducted in an attempt to understand the knowledge, experiences and actions of patients and health care professionals involved in managing COAG. This research provides a collaborative approach to designing and implementing an Expert Patient Programme and sheds light on the problems associated with managing COAG. The focus of my work has been to design, implement and evaluate a hospital based Glaucoma Expert Patient Programme (GEPP) for the purpose of improving the awareness, self-management skills and potentially concordance amongst newly diagnosed patient with COAG.

1.0 Setting the Scene

Chronic Open Angle Glaucoma (COAG) is the second most common cause of blindness and visual impairment registration in the United Kingdom (UK) (Burr et al., 2007). Though not curable, the progression of this all too common, disabling condition and can be averted through timely screening and prophylactic treatment. However, as I shall demonstrate, screening and treatment is not always timely and successful. The traditional medically led approach to managing COAG is not doing as well as it might. The problem of managing COAG is complex as timely screening and successful regimes of treatment depend on many factors, not least the actions of a wide range of health care professionals, carers and, most vitally, the actions of COAG patients. This research is an attempt to better understand the knowledge, experiences and actions of patients and health care professionals involved in managing COAG by devising a collaborative approach that is likely to improve concordance and quality of life. Thus the collaborative methodological approach of Action Research has been adopted to study how the collaborative practices of implementing an Expert Patient Programme sheds light on the problem of managing COAG to produce a better outcome.

The Expert Patients Programme (EPP) is defined by the Department of Health (DOH, 2001) as a self-management programme for people who are living with a chronic (long-term) condition. The aim of such programme is to increase their confidence, improve their quality of life, and help them manage their condition more effectively.

The research presented in this work seeks to explicate the development and implementation of a specifically designed Glaucoma Expert Patient Programme (GEPP) and to unpick the reality of self-management in this particular chronic disease. The purpose of this chapter is to set the scene for the reader with three main areas highlighted. First, a focus on the increased prevalence of COAG and its' associated problems of concordance and healthcare costs. Second, the rise of active patients and self-management programmes in healthcare. Third, the rational for the research will be introduced, and finally some light will be shed on the history of Action Research.

1.1 The Rise of COAG Associated Concordance and Health Care Cost

People in the developed world have experienced the "epidemiological transition" where there was a shift in the disease burden from high rates of death from acute, parasitic, infectious diseases, and short life expectancy to longer life expectancy and high rates of chronic diseases (Harwood et al., 2004; Cockerham, 2001). Globally, the World Health Organisation (WHO, 2002) estimates that 4.5 million people are blind due to glaucoma accounting for 12.3% of global blindness (Resnikoff et al., 2004). In the UK, COAG is the second commonest cause for registration as blind (17.000 people approximately) and visually impaired (15.500 people respectively) (The Information Centre, 2006). In the UK, it also accounts for 11.6% of registrations over the age of 65 years, although this is likely to be underestimated because of the way in which it causes blindness in patients with more than one pathology assigned to varying prevalence surveys, and because most blindness surveys do not consider subjects functionally blind due to severely restricted visual fields (King et al., 2010).

A substantial increase in individuals affected with COAG and the subsequent costs is predicted over the next few years due to two primary reasons. First, by 2030 it is predicted in the UK that the population of all those under 44 years of age is set to fall; the 60-74 age group will rise by about 50% and the over 75 age group is likely to increase by 70% (Bootle, 2005). With an adult gradual onset, COAG is estimated to be present in around 2% of the population over the age of 40 years, rising to almost 10% of those older than 75 years in white Europeans. The prevalence may be higher in people of black African or black Caribbean descent who have a family history of glaucoma (NICE, 2013). With changes in population demographics as people grow older and living into their 70s and 80s, the number of individuals affected is to expected to rise (NICE, 2013; Rudnicka et al., 2006). Secondly, the recent National Institute of Clinical Excellence (NICE) guidelines (NICE, 2011) have strongly advised community eye health services (i.e. Optometrists) to refer all persons measuring an intraocular pressure (IOP) of >21mmHg for assessment by an Ophthalmologist as compared to IOP of >25 mmHg in the past. This means all cases of suspected glaucoma will be referred to secondary care for confirmation of the diagnosis and treatment where necessary. This will inevitably increase the number of cases being diagnosed with COAG (Vernon, 2011). Those most at risk include the socially disadvantaged with no family history of glaucoma, those with high IOP and those who do not attend an optometrist regularly (King et al., 2010).

Therefore, with this predicted increase in number of individuals affected and the subsequent costs, it is timely and essential to identify an effective strategy and self-management programme that will help improve the quality of life of these individuals as well as minimising the burden of this condition on an already overstretched NHS services.

Although glaucoma cannot be cured and damage already done to the optic nerve cannot be reversed, early treatment can slow down its progress, often by a course of eye drops that help to reduce pressure inside the eye. Early diagnosis can mean the difference between serious and permanent sight loss and indefinite good vision, which is one reason why regular eye tests are so important. Evidence suggests that people from underprivileged areas who have a lower occupational status and a lower level of education are more likely to present late for detection and treatment, significantly increasing their risk of permanent sight loss from this condition (Fraser et al, 2001). Glaucoma is therefore one of the conditions that reflects health inequalities between different socioeconomic groups (Rudnicka et al., 2006). A more collaborative approach to health care research of the processes involved in screening might well be able to address this inequality in health. Additionally, this research is aimed at raising the profile of COAG and increasing community awareness by utilising Expert Patients who may be able to promote the importance of screening to other members of their families who are at risk. This will, potentially, trickle through the community and they will be more aware of the disease and the help that is available.

Whilst the human cost of living with impaired vision or no vision at all can be immense, so too is the financial cost to the state. Reviewing the literature revealed very little attention paid to the financial cost of glaucoma. A review by Kobelt (2002), explained that as the disease affects mainly the elderly; there is considerably low investment and there is a lack of new treatments under development. A relatively old review conducted by Ethical Strategies Limited in 2003 estimated the annual costs for those registered as blind or partially sighted in England alone ranges from £1.4 to £2.9 billion (Grainger and Hutchinson, 2003). A more recent review based on the Royal National Institute for the Blind (RNIB) (2008) estimated sight loss cost of at least £6.5 billion and this is likely to increase as the number of people with sight loss increases with average costs per patient ranging from £7,239 to £17,246 (RNIB, 2011) per annum.

It is therefore unsurprising that governments in the developed world are focusing on initiatives and models that seek to reduce this cost (Wilson et al., 2005). Many of the most common chronic diseases unlike COAG are preventable, however, the trends and evidence available suggests that current medical model attempts to engage the public in changing lifestyle behaviours have not been successful (Wanless, 2002). In an attempt to fully engage the public, recent policies have heavily promoted the collaborative notion of the active patient. The key example of this is the Expert Patient Programme (EPP) (Department of Health, 2001), a lay-led self-management programme for generic chronic diseases that enables patients with chronic illness to self-manage their conditions (Kennedy et al., 2007) and thus be concordant with recommended treatment modalities.

1.2 The Nature of the Problem

As indicated in section 1.0 of this Thesis, COAG is a potentially blinding condition and the second most common cause of blindness and visual impairment registration in the UK (Burr et al., 2007). It is usually asymptomatic until advanced and many people will be unaware there is a problem with their eyes until severe visual damage has occurred; hence it is often called the "sneak thief of sight". The term chronic means "over time" and in this condition pressure within the eye increases very slowly and painlessly. So slow is its progression that the brain is capable of adjusting to the loss of vision, so that no visual impairment is immediately apparent. By the time symptoms become apparent, it is often too late to reverse the condition (Rudnicka et al., 2006).

By its nature, long term conditions like COAG require day-to-day management to prevent conditions worsening. This task falls far more to individuals and their family members than to health professionals (Vernon, 2011). There are 8760 hours in a year and the average person with COAG spends on average 3 or 4 hours a year with health professionals; that is less than 0.05% of the year (Alakeson, 2011). However, the current medical model and technologies have failed to provide a cure for COAG or even solutions for problems associated with its treatment. Furthermore, strategies attempting to encourage patients to comply with their treatment have not been successful. Writers in the field have argued that the solution is one that requires a different practice of health care, with new roles for the patients, for doctors and nurses, and for health services (Holman and Lorig, 2004; Lorig et al., 2001).

In the narrative that follows the reader is given a brief explanation of the current and culturally dominant model of health care in the NHS, which is best termed as the medical model or sometimes referred as biomedical model (Wade, 2009). According to its founding concepts, diseases, including mental illness are explained as abnormalities in the function of genes, cells, organs, and biological systems, caused chiefly by trauma, and neurophysiological dysfunction (Shah and Mountain, 2007). Treatment in this model generally consists of repairing and removing (surgery), attacking (antibiotics, anti-cancer agents), or modifying (hormone therapy) the entity causing the disease or trauma. According to Thomas (2004), the medical model is characterised by:

- High cost and profitability
- Sophisticated testing and vast range of therapies and drugs
- Good short-term outcomes and fair long-term outcomes
- High-tech research
- Development of new knowledge
- Difficulty addressing chronic disease.

Although we have recently witnessed a new era of patient involvement and introduced Expert Patients, there are indications that there has not been a corresponding paradigmatic shift in the power that controls patient involvement or in the health professions that still view patients as merely passive recipients of health care (Holman and Lorig, 2004). Numerous studies have been conducted on doctor-patient relationships. These indicate that patients continue to be reticent in sharing their viewpoints within the consultation (Britten et al, 2004; Stevenson et al., 2003). Collaborative initiatives like an Expert Patient Programme and self-management programmes that are promoted heavily by the government and believed to be effective in improving self-efficacy and self-management amongst patients with chronic illnesses still face a considerable resistance from health professionals towards this notion (Henderson, 2003).

The aims of this study have been to design, implement and evaluate a disease-specific Glaucoma Expert Patient Programme (GEPP). The programme is hospital based in the sense that it intends to complement the advice and actions of health professionals working in the health service. The research explored the impact of this programme on newly diagnosed glaucoma patients, as it initiated behavioural changes and developed constructive self-management strategies based on sharing the knowledge and expertise of Expert Patients to motivate them to assume greater responsibility for their health care.

1.3 Changing Terminology

Patient adherence with chronic medical treatments is known to be far from ideal (Schwartz and Quigley, 2008). The terminology used to denote individuals' behaviour towards medication use has become more precise and empowering over time. Whilst this terminology will be discussed further in Chapter Two, it is appropriate to draw the readers' attention to some of the terms that are widely used. Although the term 'compliance' is now well respected in the medical literature; it implies obedience to health professionals and reflects a paternalistic attitude. The term 'adherence' may be a better term and more precise but it remains slightly judgmental. 'Concordance', introduced in late 1990s is intended to remove the implication of submissiveness to health professionals and introduce a more collaborative approach to health care. It should be noted however that the majority of practitioners working within the field of ophthalmology and authors of articles and other texts related to ophthalmic research and ophthalmology predominantly use the term adherence (Amro et al, 2011a, Amro et al, 2012).

This study has explored how truly involved and informed participants can work to build a rapport and collaborate with health professionals to improve eye health outcomes. It has adopted a patient-centred approach that helps to move away from the traditional paradigms that view the patient as a mere recipient of doctor instructions. Using the appropriate terminology has been problematic; particularly in the medically dominant setting of Moorfields Eye Hospital National Health Service (NHS) Foundation Trust. As the term 'concordance' has not been fully recognised for use in this clinical setting, there has been a general lack of understanding of the implications of this term in comparison with terms like adherence and compliance. The Research and Development Committee at the Trust was in favour of using adherence as concordance is viewed as ambiguous and at times imprecise. Therefore, to save any further confusion and for clarity in this Thesis, the term 'adherence' will be used interchangeably with the term "concordance" throughout the Thesis to refer to patients' behaviour toward medication use.

1.4 Contexts and Justification for the Research

The epidemiological transition of healthcare from acute to chronic disease management has been encouraged by a growing recognition of the central role that individuals can play in managing their own health (Lorig at al., 2001). This transition has led to a new focus on interventions that support self-management, such as the NHS Expert Patient Programme (EPP) (Sullivan, 2003). It has also strengthened the call for the need to change service arrangements and transform the NHS away from a professionally driven model of healthcare management to one that is individually tailored based on partnership between individuals, families and professionals (DoH, 2008).

One aspect of this desired change has been to encourage patients to become actively involved in the management of their condition (Holman and Lorig, 2004). The day-to-day responsibility for chronic disease self-management is gradually shifting from health care professionals to the individual (DoH, 2005). Active involvement of patients could potentially result in better concordance to management and improved management of long-term conditions without increasing costs (Duffy, 2007).

Evidence indicates that between 30 and 50% of patients do not take their prescribed medication in full and that the annual cost of wasted drugs in the UK is around £100 million (DoH, 2008). For decades, the traditional approach to patients with COAG has been primarily pharmacological and if unsuccessful, often combined with surgical intervention. Although useful, evidence shows that patients with COAG have one of the poorest levels of concordance. NICE (2011) indicate that involving patients and helping them understand how to manage their COAG could potentially improve concordance to medical treatment; allowing them to remain sighted for longer.

The government commitment to promoting and embedding self-management programmes within the NHS was set out in a key policy document entitled: 'The Expert Patient: a new approach to chronic disease management for the 21st century'; published by the Department of Health (DoH) in 2001. This document raises fundamental questions about the ability of such a programme to change chronic disease management in an organisation like the NHS. It also raises key questions as to whether a generic programme is suitable for all chronic conditions, or whether patients and health care professionals will engage and accept such a programme. For example, a national review of the Expert Patient Programme was conducted by the National Primary Care Research and Development Centre (NPCRDC) (Kennedy et al., 2007) and raised concerns about its effectiveness. Several reviews and a Meta-analysis commissioned by the Cochrane Collaboration have reviewed the effectiveness of the self-management programmes in various contexts and populations.

The focus of my work has been to design, implement and evaluate a hospital based Glaucoma Expert Patient Programme (GEPP) for the purpose of improving the awareness, self-management skills and potentially concordance amongst newly diagnosed patient with COAG. This Thesis aims to show how effective the GEPP is in improving awareness, satisfaction and concordance of newly diagnosed patients.

1.5 Methodological Account

In this study three different methodological approaches were applied to three different stages, Ethnography, Action Research, and Mixed Methods. The Ethnographical approach was used to explore the issues arising from designing the GEPP, whilst a collaborative Action Research approach was followed when examining the implementation of the GEPP. A Mixed Method approach was used when examining the effectiveness of the intervention and the issues arising from its delivery. Ethnography is a research approach that has traditionally been used to understand different cultures and in the first part of the study it guided the research process. Action Research on the other hand linked the research back to the aims and objectives of this study.

Ethnography fits very well with action research because they both try to understand how a particular target group and a particular research work together (Alasuutari, 1995). In contrast to the dominant biomedical model, it was important to consider how to explore forms of knowledge and the lack of it at times. Ethnography is an approach to research. It is not one specific method (like participant observation, or interviews, or surveys). In fact, it is a multi-method approach. I used a mixture of methods where appropriate to the situation and I adapted each method to the situation. To clarify, simple observation without being an active participant may not have been sufficient for exploring a situation where there is an obvious lack of knowledge and potentially 'hidden' dissatisfaction.

There is uncertainty over the use of action research with diverse claims for and against action research in a variety of contexts (Masters, 1995). Authors such as Kemmis and McTaggert (1988), Zuber-Skerrit (1992), Holter and Schwartz-Barcott (1993) claimed that American psychologist Kurt Lewin first used action research in 1946. However, McKernan (1991) argued that a number of social reformists used action research prior to Lewin. Despite the ambiguity of its origin, Kurt Lewin constructed the first action research theory in the 1940s (Lewin, 1948). Lewin envisioned action research as a cycling back and forth between ever deepening surveillance of the problem situation (within the persons, the organization, and the system) and a series of research-informed action experiments. His original formulation of action research "consisted in analysis, fact-finding, conceptualisation, planning, execution, more fact-finding or evaluation; and then a repetition of this whole circle of activities; indeed a spiral of such circles" (Sanford, 1970:4). In Lewin's paper, he identified a framework for action research that proceeds "in a spiral of steps, each of which is composed of planning, action, observing and the evaluation of the result of actions" (Carr and Kemmis, 1986:8).

However, a number of other people must take credit for their contribution in the development of action research over the years other than people who are reported in the literature (Gunz and Jacob, 1996). Jacob Moreno (1892-1974), a physician, social philosopher and poet who shared students with Lewin, reported the importance of integrating theory and practice by perceiving researchers as social investigators rather than just observers (Waterman et al, 2001). With an increasing popularity over the last two centuries, action research has been used in a wide range of fields including organisational development (Coghlan and Brannick, 2005), education (Carr and Kemmis, 1986), community development projects (Reason and Bradbury, 2001) and health (Meyer, 1993; Waterman et al, 2001).

1.6 Study Population

The population targeted in this research was relatively diverse, ranging from patients attending the clinics, relatives and carers, Expert Patients, administrative staff, nursing staff, Optometrists and Ophthalmologists. My broad criterion for inclusion was anyone who was involved in any capacity or role in caring for patients with COAG. On any given day, there will be between three to five glaucoma ophthalmologists, one or two optometrists, three to five nurses and two to three clerical administrators. On average, each one of the research site clinics attends to 50 to 80 glaucoma patients per day, with a large proportion of these patients being seen in the morning sessions.

1.7 Research Site

A critical step in this study was gaining entry into the area being studied (Burns and Grove, 1993). My second supervisor and clinical facilitator, a lead glaucoma consultant at Moorfields Eye Hospital NHS Foundation Trust Glaucoma Services, introduced me to people running and managing the glaucoma services in the trust. Of whom, a few I had worked with before in the A&E Department. They were incredibly supportive and gave me the time and space to get on with my study. I would not be that fortunate had I been an outsider conducting this enquiry. Further discussions and informal conversations made the purposes and methods of this study clearer to professionals running the clinic. I made it clear what the purpose of my observations and my intentions in conducting this study were which made my period of observation a pleasant experience.

1.8 Demographics of the Research Community

The research was undertaken in the London Borough of Barking and Dagenham. The local population of the London Borough of Barking and Dagenham is growing at a significant rate. The latest estimate of the population of this Borough is 170,000 that represent an increase of more than 6,000 from the census figure of 163,944 in 2001. By 2020 the population is expected to reach 208,000, which is an increase of 38,000.

According to the Barking and Dagenham Joint Strategic Needs Assessment (JSNA) of 2009, about 27% of residents in the Borough are from Black and Minority Ethnic groups in comparison with 12.5% the national average in England. I hoped that by selectively choosing a community where ethnic minorities are over represented, in comparison with the national figures and other neighbouring boroughs in London, that it would increase their chance of representation in the overall sample of this study.

1.9 Economic Disadvantage and Low Levels of Education

The levels of deprivation in this borough are quite high. Barking and Dagenham is the eleventh most deprived district in England (out of 354) and the sixth most deprived borough in London. Residents have the lowest average income in London. Barking and Dagenham's population has the fourth lowest literacy levels and second lowest numeracy levels in England. The borough has the lowest percentage of 16 to 74 year old residents with qualifications in London.

Low levels of literacy make it more difficult to raise awareness regarding preventable sight loss and educate people about healthy living. Economic disadvantage means that many people may face sight loss that could be avoidable by presenting to the Optometrist clinic and having a simple eye test. Free NHS eye tests and those with a family history of glaucoma are available to people receiving certain benefits, and free examinations are on offer for people over 60; yet cost still appears to dissuade many people from having their eyesight checked.

1.10 Research Question, Aims and Objectives

This study has aimed to explore the concept of an Expert Patient Programme by designing, implementing and evaluating a glaucoma intervention programme for the purpose of improving newly diagnosed COAG patients' knowledge and concordance with treatment regimens. Expert Patients were trained and supported to take on the role of delivering a one-to-one intervention (educational programme) with newly diagnosed fellow glaucoma patients.

The following is the specific research question addressed in this study:
"Does development and implementation of a GEPP improve knowledge and concordance amongst newly diagnosed glaucoma patients?"

The objectives of this research were:

1. To determine through semi-structured interviews peoples' (Expert Patients, Patient Participants and staff) perception of the GEPP.
2. To determine through questionnaires whether knowledge and concordance improved immediately following exposure to the GEPP.
3. To determine overtime whether knowledge and concordance are maintained.

1.11 Organisation of the Thesis

The next chapter of this Thesis provides an overview of the challenge of COAG highlighting presentation and patient pathways, demographic and epidemiological trends, a meta-analysis of self-management programmes, clinical management of COAG and associated problems. Chapter three presents the themes from a literature review of self-management in chronic diseases. Drawn into this chapter is an analysis of strategies to promote self-management, theories and policies surrounding chronic conditions. An Adherence Model for the GEPP is discussed and the Information-Motivation-Behavioural (IMB) Skills Model, as the theoretical framework for this study, is presented and critiqued. Then the work is presented in two parts in chapter four. Part One describes the Ethnographic approach that addresses the design of the GEPP. This is followed by Part Two in which collaborative Action Research as a new paradigm in social inquiry is explored alongside the Information-Motivation-Behavioural (IMB) Skills Model for implementation of the GEPP.

In chapter four a detailed account of this inquiry and where I stand as an insider-outsider researcher with experience as an ophthalmic nurse is provided as well as examining the effectiveness and interpretations from the intervention delivered. Chapter five presents the findings of the research from the perspective of designing, implementing and evaluating the study. Findings are presented qualitatively and quantitatively. An overall discussion chapter will be presented in chapter six including a reflection of the methodological approach and the empirical and theoretical contributions of the research. Finally, recommendations and conclusions will be presented in chapter seven.

CHAPTER TWO

The Challenge of Chronic Open Angle Glaucoma

2.0 Introduction

This chapter is presented in three sections. The first section provides an overview of the nature of COAG as a chronic condition, the clinical features and presentation, patient pathways; epidemiological trends of COAG, treatment options and prognosis are also reviewed. The second section delineates and contrasts literature that provides examples of how self-management programmes are perceived and described within the bio-medical perspective in a meta-analysis. The last section explicates challenges faced by individuals affected by COAG and proposes an alternative "collaborative approach" to its management. This chapter concludes by summarising COAG, its risk factors and adherence to treatment regimens.

Section I: Understanding COAG

2.1 Definition of Glaucoma

Glaucoma is a chronic degenerative optic neuropathy in which the neuro-retinal rim of the optic nerve becomes progressively thinner, thereby enlarging the optic-nerve cup (Ferri, 2012). To understand COAG better, it is important first to consider the functional anatomy of the eye and aqueous dynamics.

2.1.1 Functional Anatomy of the Eye

First the act of seeing (vision) is explained. Vision transpires in several steps. Light enters the eye through the cornea and the crystalline lens to the retina; the retina then 'transforms' this light into electrical nerve impulses that the brain can process (refer to figure 2.1) (Kanski and Salmon, 2003). Once the light has been focused on the retina, it is absorbed by the retinal photoreceptors (the rods and cones) and the information transmitted to retinal ganglion cells (axons). All visual information is then sent as nerve impulses through the optic nerve to the part of the brain called the visual cortex.

Figure (2.1): The Eye: Adapted and Reproduced from the Department of Work and Pensions (2010).

Retinal ganglion cell axons converge at the optic disc from where the optic nerve emerges; in other words, the optic nerve connects the eye with the brain (Flammer, 2003). Now the visual system is able to put together images formed in each eye. Throughout the course of a lifetime, even a healthy person will lose some nerve fibers as part of the natural ageing process.

2.1.2 Aqueous Dynamics

The eye maintains its spherical shape because it is 'inflated' to above atmospheric pressure. The normal range of intraocular pressure (IOP) is between 10 and 21 mmHg. Aqueous humour is a clear fluid formed by the ciliary epithelium through active secretion, ultra filtration and diffusion. The function of this fluid is to provide nourishment for the cornea and the lens whilst giving the eye its shape and contour. Aqueous initially passes into the posterior chamber between the iris and the lens then into the anterior chamber through the pupil. Then it leaves the anterior chamber into the trabecular meshwork and Schlemm's canal where it flows through collector (refer to figure 2.1 and 2.2) (Kanski and Salmon, 2003).

Figure (2.2): Angle-closure on the right; on the left open-angle glaucoma: Adapted from QwikStep (2011).

This route accounts for 90% of aqueous drainage; the remaining 10% are drained through the ciliary body in the chamber angle into the venous system. A very small amount of the aqueous is also drained away through the corneal epithelium, iris vessels and vitreous humour (Kanski and Salmon, 2003). It is the abnormalities and imbalance between the production and drainage of the aqueous that leads to an increased IOP and to glaucoma. The exact mechanism that control and maintain the IOP within the normal range is unknown.

2.1.3 Classification of Glaucoma

The term 'glaucoma' covers a wide range of diseases having three things in common which are an optic neuropathy (Burgoyne et al., 2010), visual field loss and irreversible blindness (Ferri, 2012). These ocular diseases may cause characteristic progressive changes in the optic nerve head, visual field loss, or both (Edgar and Rudnicka, 2007) which can progress to involve the fovea and central vision (Tielsch, 1996; RCO, 2004).

There are a number of different types of glaucoma and these can be classified according to three main factors. These are: the appearance of the drainage angle (open or closed) which directly relates to the anterior chamber angle and the region for aqueous drainage as illustrated in figure (2.2), the presence of contributing factors that may raise the IOP and other conditions such as inflammation and nonvascular disease that may lead to secondary glaucoma. Chronic Open Angle Glaucoma is the most common form of glaucoma in the UK and therefore the remainder of this chapter and Thesis will focus primarily on this condition.

2.1.4 Chronic Open Angle Glaucoma (COAG)

COAG is the most common type of glaucoma in Western Europe. It is the leading cause of blindness in African-Americans in the United States of America (USA) and the second leading cause of blindness worldwide. It is estimated that 13.5 million people may have glaucoma and 5.2 million of those are blind. In the UK, it is responsible for 12% of blind registration (IGA, 2012) and 12.3% globally (Resnikoff et al., 2004)

COAG has an adult onset, usually bilateral (although not always symmetrical) and produces characteristic changes in the optic nerve head or visual field with or without an onset of increased IOP greater than 21 mmHg with an absence of underlying cause (RCO, 2004). Open-angle glaucoma means that when examining the anterior chamber angle, there is nothing that could block the aqueous humour outflow, but nevertheless, the IOP is elevated (Flammer, 2003). Refer to figure (2.2) for an illustration of the anterior chamber angle.

In COAG, the mechanism of damage involves an increased resistance to aqueous outflow within the trabecular meshwork (a circumferential sieve-like structure through which 90% of the aqueous drains) so causing a rise in IOP (Flammer, 2003). This in turn influences retinal ganglion apoptosis: the rate of which is influenced by the IOP itself mechanically increasing pressure on the optic nerve head by compromise of the local microvasculature (AAO, 2005).

In COAG, the nerve cells and nerve fibers progressively die at a faster rate. As a consequence, the connection between the eye and brain, so crucial for vision, is gradually severed (Morgan, 2004). The eye at this stage still sees the light because the rods and cones are still working, but the transmission of visual information to the brain is interrupted (Hayreh, 2001). This is the core of the problem and is termed "glaucomatous damage". Hartmann as a long sufferer of COAG wrote in the British Medical Journal about her own journey as a patient and provided this definition:

> *"When I try to explain what it's like not to see with glaucoma, I tell people to imagine a digital TV screen with pixels and to imagine that some of the pixels in an area have ceased to function. The entire picture still exists and moves, but there are areas that simply disappear from the screen. There is no shadow, no light, no colour—just nothing"* (Hartmann and Rhee, 2006:738).

2.2 Risk Factors for COAG Onset and Progression

In recent years, substantial information has been added to our knowledge about risk factors for Chronic Open-Angle Glaucoma. Several studies have evaluated the cross-sectional association between risk factors and COAG, whereas only a few have investigated the risk factors for the development of glaucoma and its progression (Boland and Quigley, 2007).

Risk factors for COAG are statistically associated with the development of COAG whereas prognostic factors for COAG are statistically associated with the progression of COAG. Neither risk factors nor prognostic factors establish causation. Prognostic factors for the progression of COAG have been explored in four large multi-centred clinical trials (Coleman and Miglior, 2008). The most consistent prognostic factors are older age and higher baseline IOP. Lowering IOP medically or surgically remains the only consistent strategy to slow the progression of COAG (Leske et al., 2007).

Identifying risk factors has preventive and therapeutic implications in COAG. With the absence of a way to prevent the development and progression of glaucoma, numerous investigators have studied the characteristics of individuals who have glaucoma, and based on those studies it became possible for them to identify several factors that seem to occur more frequently in glaucoma patients. Since there is a greater likelihood of these factors being present in someone with glaucoma, it is reasonable to assume that these are considered as risk factors for glaucoma. Some risk factors are immutable (genes), whereas others are variable and even amenable in the presence of strategies to modifying risk factors. The following table provide a summary of the main risk factors identified in the literature.

Table (2.1): Risk Factors of COAG

Risk Factors for COAG	**Occular Factors**	Intraocular Pressure
		Optic Disc Changes
		Visual Field Loss
		Short and Far Sightedness
	Demographic Factors	Age
		Socioeconomic Status, Alcohol Drinking and Smoking
		Gender
		Ethnic Background
		Familial Factors
	Systemic Diseases Risk Factors	Diabetes
		Hypertension

2.2.1 Ocular Factors

Currently several risk factors have been identified for glaucoma but as yet the underlying cause is not known. It is been suggested that a combination of risk factors such as decreased blood flow to the optic nerve head and IOP levels that are too high in an individual may contribute to ganglion cell death (Morgan, 2004).

2.2.1.1 Intraocular Pressure (IOP)

IOP is a little like blood pressure in that there is not an absolute correct value but a normally distributed range of values (from 10-21mmHg) with some normal individuals having IOPs outside these ranges (IGA, 2009). IOP is the main established factor, as the risk of COAG increases with increasing levels of IOP (Johnson et al., 2003). Numerous experimental studies and clinical and epidemiological observations support the view that the higher the IOP, the greater the likelihood of glaucoma (Nemesure et al., 2007). Epidemiological studies have compared the lowest and middle IOP groups and show an increase in COAG prevalence with increasing IOP as approximately six-fold, and about 16-40 fold comparing the lowest and highest IOP groups as illustrated in table (2.1) (Sommer et al, 1991; Mitchell et al, 1996).

Table (2.2): Prevalence estimates of COAG according to IOP.

Baltimore Eye Study (Mitchell et al, 1996)		Blue Mountains Eye Study (Sommer et al, 1991)	
IOP (mmHg)	Prevalence of COAG (%)	IOP (mmHg)	Prevalence of COAG (%)
16-21	1.5	12-13	0.9
22-29	8.3	22-23	5.7
≥30	25	>28	39

Recently, epidemiological studies have revealed the presence of glaucoma without raised IOP, and raised IOP without glaucoma, which has led to re-evaluation of the relationship between the two (Hatt et al., 2006). Johnson et al. (1998) argued that the diagnosis of COAG cannot be made on the basis of IOP alone, but having an arbitrary cut-off of 21mmHg increases the efficiency of case findings.

2.2.1.2 Optic Disc Changes

As COAG can occur in eyes with normal or raised IOP, there is increasing emphasis placed upon optic disc changes (RCO, 2004). This is a key assessment as it is a direct marker of disease progression.

The greater the tissue damage at the optic nerve head, the more likely a future progression of nerve fibre loss; but whether this is a genuine risk factor is still debated (Flammer, 2003). Theoretically, it seems possible that an already damaged optic disc could be more susceptible to increased IOP. Optic disc damage is assessed by examining the vertical ratio of the pale centre (cup) to the overall size of the disc. A small cup and a thick neuro-retinal rim (the darker part surrounding the cup) may give a ratio of 0.3 or less (normal) (RCO, 2004). A small number of people have a cup: disc ratio up to 0.7 but anything beyond that is definitely pathological (Tielsch, 1996). These measurements are not risk factors in an aetiological sense, but observation undertaken by an examiner will determine whether progression has occurred.

2.2.1.3 Visual Field Loss

Loss of visual field results from damage to nerve fibre bundles as they enter the optic disc. When a bundle of nerve fibres is damaged and lost, certain areas of the retina lose their innervations resulting in a visual field loss in the upper or lower half of the field. Such loss is initially only minimal but is gradually progressive and may eventually result in total blindness if the disease is not treated. There are different tests that are used widely in ophthalmic settings to assess patient's visual field, which will be discussed later on in this chapter.

2.2.1.4 Short and Far Sightedness

An eye may be normal-sighted (emmetropic), meaning no visual correction is required, far-sighted (hypermetropic) or near-sighted (myopic). Healthy hypermetropic and myopic eyes have the same mean IOP as emmetropic eyes (Flammer, 2003). However, since myopic eyes are, on average, larger than normal eyes, there is a high risk of COAG and other eye diseases independent of glaucoma. The association of COAG with myopia has been shown in several case-control studies (Johnson et al., 1998). However, there is a potential for selection bias, because those with myopia are more likely to seek eye care and have a higher probability of being diagnosed with glaucoma compared with people without refractive errors (Tielsch et al., 1994).

2.2.2 Demographic Factors

These are factors that can have a more or less pronounced influence on the intraocular pressure. These factors are discussed here.

2.2.2.1 Age

Glaucoma is strongly associated with age and particularly so in COAG. Although children; even newborns, can suffer from glaucoma, it is very rare; most patients having an elevated IOP are over the age of 40 (Mitchell et al, 2002). Throughout a person's lifetime, even in healthy eyes, there is a gradual rise in the IOP. This is due to the ageing of the trabecular meshwork, however, the production of the aqueous humour decreases during the same period, so the IOP rise is usually quite moderate (Azuara-Blanco et al., 2002). For most COAG patients, the IOP starts to rise between the age of 40 and 50. In other patients, the IOP rises at a later age (Leske, 2007).

In a meta-analysis, it was shown that the prevalence of COAG rose steadily with age and more steeply in Europeans than in other populations, but at all ages black populations have the highest prevalence estimates (Rudnicka et al., 2006). Without treatment, the pressure continues to rise over the years. The exact nature of the changes in the eye related to age that also accounts for the development of COAG is not known (Johnson et al., 1998).

2.2.2.2 Socioeconomic Status, Alcohol Drinking and Smoking

Eye problems like many other health problems are more prevalent in people living in relatively underprivileged areas (Reidy et al, 1998). In addition, uptake of eye examination is low amongst individuals coming from unskilled socioeconomic groups (Wormald et al, 1997). Hence, those who have the least material and psychosocial resources to cope with blindness may be at substantially higher risk of glaucoma and glaucomatous visual loss (Fraser et al, 2001). Whether this is a reflection of the social class variations in the prevalence or incidence of COAG (Reidy et al, 1998), or that those from less privileged circumstances present with different stages of glaucomatous disease remains unclear (Fraser et al, 2001). Either way, it is a health inequality that needs to be addressed.

Epidemiological studies are yet to show whether alcohol consumption and smoking, which are known to be associated with socioeconomic factors, have any evident effect on the prevalence of COAG (Quigley et al, 2001). Bonovas et al. (2004) conducted a systematic review and a meta-analysis of four case-control studies and three cross sectional studies. They found that current smokers were 1.37 times more likely to have

COAG than non-smokers. More data from epidemiological studies is needed and the analysis should take into account risk factors that are related to socioeconomic status.

2.2.2.3 Gender

The relationship of gender to risk of COAG is inconsistent as men and women have the same IOP levels (RCO, 2004). The Farmingham and Barbados Eye Studies found that men had a significantly higher prevalence of COAG than women across all racial groups (Leibowitz et al., 1980; Rudnicka et al., 2006), whereas the opposite was found in Sweden (Bengtsson, 1981) and no association was found in Wales (Foster et al., 2002). Thus, gender is unlikely to be a major risk factor for COAG (Tielsch, 1996). However, Mitchell et al (2002) asserts that not only women commonly afflicted with normal tension glaucoma but also women with COAG and high IOP have a slightly higher risk of developing glaucomatous damage at a certain pressure level than do men.

2.2.2.4 Ethnic Background

Racial variations in the risk of COAG are an important part in the epidemiology of the disease (Tielsch, 1996). Although it is sometimes not easy to separate the influences of the prevailing socioeconomic conditions, nevertheless, patients of African ancestry often have a higher IOP and develop elevated IOP at earlier age (Leibowitz et al., 1980). The reason for the excess risk among persons of African descent is not clear, but it is likely to be related to an underlying predisposition (Tielsch et al., 1994). Caucasians, on the other hand, suffer more frequently from pseudoexfoliation glaucoma particularly in the northern European countries. This study was mainly based in the East London borough of Barking and Dagenham. The population of Black and Ethnic Minorities in Barking and Dagenham has risen by 158% from 9,779 in 1991 to 25,257, in 2001. These figures have almost tripled in recent surveys with rising levels of inequalities.

Engaging affected individuals from Black and Minority Ethnic (BME) populations can be challenging. There are language barriers that can have an impact on affected individuals of Asian origin, to a lesser extent on individuals of Black origin. However, BME groups tend to have the health belief that of "doctor knows best" which in itself can be a challenge in treating COAG, not only because of increased prevalence, but also in adherence to treatment. Therefore, by recruiting expert BME patients in this research, it further increases the potential to reach out to potentially disadvantaged groups.

2.2.2.5 Familial Factors

Family history is an established risk factor as the hereditability of COAG has been calculated from twin studies to be as high as 70-80% and 98% has been reported in monozygotic twins (Gottfredsdottir et al, 1999). There is a clear inherited component in many individuals (IOP, aqueous outflow facilities and disc size are inherited characteristics) (AAO, 2005). In a Rotterdam study (Wolfs et al, 1998) the lifetime risk of glaucoma was nine times higher in siblings and offspring of glaucoma patients than in siblings and offspring of controls without glaucoma. It showed almost twice higher incidence of COAG in those with a positive family history of COAG compared with those without a family history. In a similar study (Azuara-Blanco et al, 2002), individuals who have a first-degree relative with glaucoma have greater risk of up to 30% of developing the disease compared with controls. However, it is thought that there is incomplete penetrance and variable expressivity of the genes involved (Wiggs, 2007). COAG is inherited as a complex trait with unclear understanding of the inheritance patterns.

2.2.3 Systemic Diseases Risk Factors

2.2.3.1 Diabetes

While it is well documented that complications of diabetes can produce secondary glaucoma, the association of diabetes with COAG is inconsistent (Wilson et al., 1987). Johnson et al. (2003) reported the conflicting evidence to whether there is any association or not; case-control studies have given relative risks (Mitchell et al, 1996) while population-based studies have usually not found this association (Tielsch et al, 1995).

2.2.3.2 Hypertension

Systemic blood pressure has been related to COAG risk in several studies (Edgar and Rudnicka, 2007). Effects on ocular perfusion pressure mean that both systemic hypertension and hypotension have been implicated as risk factors for CAOG

(Graham, 1999). Although there is contradictory evidence from different studies (Leske et al., 2001a), there is considerable evidence that a reduction in blood pressure reduces the risk of COAG (Weih et al, 2001). Other studies have related this risk to do with age as the majority of hypertensive patients are over the age of 40 to 50 whereas young hypertensive patients seem to be protected, while older ones have twice the normal risk of developing COAG (Johnson et al., 1998).

2.3 Socioeconomic Variations in COAG

Socioeconomic status is measured by ascertaining education, income and occupation status. Current literature suggests consistent evidence for an association between lower socioeconomic status and late presentation with COAG. This inverse relationship between socioeconomic status and late presentation can be interpreted in different ways. Firstly, socially patterned differences in health seeking behaviours are likely to operate, and evidence suggests that regular sight testing is associated with higher social class as it greatly reduces the risk of late presentation (Fraser et al., 2001; Hoevenaars et al., 2006). Secondly, other socioeconomic factors include education deprivation. Literature suggests it influences awareness of the disease and the need for regular sight testing.

A Survey of Public Knowledge, Attitudes and Practices Related to Eye Health and Disease in the USA, knowledge of COAG was associated with having health insurance, higher income and higher education (Coleman and Kodjebacheva, 2011). Similar studies showed association between lower educational attainments with the lack of knowledge about COAG (Hoevenaars et al., 2006; Gasch et al., 2000). In the UK, people with late COAG were more likely to be from lower occupational classes, lack personal transportation, are less educated and rent rather than own their residences compared with people with early COAG (Fraser et al., 2001). A recently published Rotterdam Study (Ramdas et al., 2011) has claimed that socioeconomic status was not associated with the onset of COAG in a population-based prospective study. The findings of this study were inconsistent with the prior research and evidence, Coleman and Kodjebacheva (2011) commented that given that the Netherlands ranks number one in terms of equity in health care for all individuals regardless of income and education, these findings were not surprising.

By 2034, it is estimated that 23% of the UK population are expected to be age 65 and over, compared to 16% in 2009. The fastest population increase has been in the number of those ages 85 and over: the "oldest old". In 1984, there were approximately 660,000 people in the UK over the age of 85. Since then the numbers have more than doubled reaching 1.4 million in 2009. By 2034 the number of people age 85 and over is projected to be 2.5 times larger than in 2009, reaching 3.5 million and accounting for 5% of the total population. According to statistics carried out in 2008, 64% of blind and 66% of partially sighted people in the UK were age 75 or over. As people are clearly expected to live longer, so the incidence of age related sight loss due to progressive conditions like COAG will increase.

2.4 Prevalence of Glaucoma

There are many population-based surveys on the prevalence of glaucoma. Unfortunately many of the old publications do not differentiate between COAG and primary angle-closure glaucoma (PACG). However, the latter is far less common than COAG in the white population and those of European descent and therefore the estimates are likely to reflect mainly cases of COAG (Leske et al, 2001b). The following table (2.3) provides a summary of the trends of prevalence of glaucoma globally according to the ethnic group.

Table (2.3): Population-based prevalence of glaucoma by ethnic group (Edgar and Rudnicka, 2007)

Ethnic origin	Author (s)	Year	Name/location	Age group	Sample size	COAG (%)	PACG (%)
Black	Mason et al	1989	St Lucia, West Indies	30-70+	1679	8.76	-
	Tielsch et al	1991	Baltimore, USA	40-80+	2395	4.18	-
	Leske et al	1994	Barbados, West Indies	40-86	4498	6.8	-
	Wormald et al	1994	London, UK	35-60+	873	3.67	-
	Behrmann et al	2000	Kongwa, East Africa	40-80+	3247	3.08	0.59
	Rotchford et al	2003	Temba, South Africa	40-97	839	3.69	0.6
Asian	Awasthi et al	1975	Agra, India	30-70+	3603	1.33	-
	Hu	1989	Shunyi, Beijing	40+	3000	0.03	1.4
	Shiose et al	1991	Japan	30-70+	8924	2.53	0.08
	Foster et al	1996	Hovsgol, Mongolia	40-89	942	0.53	1.49
	Jacob et al	1998	Vellore, India	30-60	972	0.41	4.32
	Foster et al	2000	Singapore	40-81	1232	1.79	1.14
	Metheetrirut et al	2002	Bangkok, Thailand	60-104	2092	2.92	2.53
	Ramakrishan et al	2003	Aravind, South India	40-90	5150	1.24	0.5
	Iwase et al	2004	Tajimi, Japan	40-80+	3021	3.94	-

Eskimo	Arkell et al	1987	Kotzebue, Alaska	15-70+	1686	0.06	0.59
White	Hollows et al	1966	Frendale, Wales	40-74	4231	0.47	0.09
	Bankes et al	1968	Bedford, UK	20-80+	5941	0.76	0.17
	Leibowitz et al	1980	Framingham, USA	65-75+	2631	1.9	-
	Bengtsson	1981	Dalby, Sweden	58-68	1511	0.86	0.13
	Ringvold et al	1991	Norway	65-89+	1871	3.37	-
	Tielsch et al	1991	Baltimore, USA	40-80+	2913	1.1	-
	Klein et al	1992	Beaver Dam, USA	43-75+	4926	2.11	-
	Coffey et al	1993	Roscommon, Ireland	50-80+	2186	1.88	0.09
	Salmon et al	1993	Mamre, South Africa	40-70+	987	1.52	2.33
	Dielemans et al	1994	Rotterdam,	55-75+	3062	1.11	-
	Leske et al	1994	Netherland	40-86	133	0.75	-
	Hirvela et al	1994	Barbados, West	70-95	500	10.4	-
	Giuffre et al	1995	Indies	40-99	1062	1.22	-
	Mitchell et al	1996	Oulu, Finland	49-80+	3654	2.38	-
	Cedrone et al	1997	Castledaccia, Sicily	40-80+	1034	2.51	0.97
	Wensor et al	1998	Blue Mount, Australia	40-90+	3265	1.72	0.06
	Bonomi et al	1998	Ponza, Italy	40-80+	4297	1.4	0.61
	Reidy et al	1998	Melbourne, Australia	65-100	1547	3.04	-
	Quigley et al	2001	Egna-Neumarkt, Italy	41-90+	4774	1.97	0.1
			North London, UK				
			Proyecto, USA				

COAG: Primary open angle glaucoma, PACG: Primary angle closure glaucoma

The above table summarises the prevalence of COAG and PACG from some of the larger population-based studies. Although the methods of testing and sampling vary from one study to another depending on the criteria used for diagnosis (RCO, 2004), they give an idea of the relative prevalence in different populations. The prevalence as illustrated of COAG ranges from 0.03% in China to 8.76% in St Lucia; most of the studies in Table 2.1 are of people aged 30 years or more. The relative prevalence for COAG of those aged over 40 years in white people from Europe, America and Australia of comparable age groups is of the same order (Approximately 1-3%), whereas black populations of Caribbean origin have a higher prevalence in similar age groups. Currently the highest prevalence of COAG is reported in black populations of Caribbean origin; particularly St Lucia and Barbados (7-9%), with slightly lower prevalence (3-4%) in black populations of African origin (Leske et al, 2001b). More up-to-date surveys have shown higher prevalence in Africa, with prevalence estimates up to 8% in Ghana (Ntim-Amponsah et al., 2004). An even higher prevalence of up to 9% was found amongst African-Caribbeans, who originate mainly from West Africa where rates are elevated (Kosoko-Lasaki et al., 2006).

Leske (2007) observed that prevalence rates tend to be higher in the most recent surveys in comparison to old surveys. This increase in the rates could be down to the increased awareness of people and so seeking expert opinion and screening tests. According to Leske's study of populations of 40 years and older, a prevalence of around 1-3% in Europe, 1-4% in Asia, and 2-3% in Australia was reported.

An interesting observation in nearly all the population surveys is that approximately half of the cases of COAG detected at the time of the survey were previously undiagnosed. It comes as no surprise that COAG is the leading cause of irreversible blindness throughout the world, placing high emphasis on screening programmes (Johnson et al., 2003). COAG accounts for most cases of glaucoma with around 2% of people older than 40 years having the condition, rising to almost 10% in people older than 75 years in white Europeans. As previously indicated in the UK, approximately 12% of blindness registrations are attributed to glaucoma (NHS Evidence, 2009).

Epidemiology has made many crucial contributions to advance knowledge on COAG. Firstly, recent epidemiologic studies have documented the frequency and distribution of COAG in many populations as explained earlier. These studies have considerable scientific and public health implications (Leske, 2007). They show glaucoma disparities by ancestry, as well as the considerable amount of cases that remain undetected which is at least half in most studies (Wolfs et al., 1998). Secondly, risk factor identification allowed the recognition of groups at higher risk and so provided strategies to target these groups for early detection, such as family members of glaucoma patients (Leske et al., 2001b). Finally, additional epidemiological contributions include the analysis of longitudinal data to identify factors predictive of progression of COAG. Identifying such factors will help in the management of glaucoma patients (Gordon et al., 2002).

2.5 Incidence of COAG

There are fewer studies of glaucoma incidence. Farmingham and Ferndale prevalence studies gave a 5-year incidence of 0.2% at age 55 years, increasing to 1% at 75 years (equivalent to 4 per 10000 per year and 20 per 10000 per year respectively) (Leibowitz et al, 1980). Bengtsson (1981) reported 24 per 10000 per year in Sweden in those over 55 years of age. In the Melbourne Visual Impairment study the incidence was reported at 12 per 10000 per year in those aged 60-69, 28 per 10000 per year in the 70-79 age group and 82 per 10000 per year in those aged over 80 years (Le et al, 2003).

Longitudinal follow up of the Barbados Eye Study (Leske et al, 2001b) showed a higher incidence amongst Black Caribbeans. The 4-year risk of COAG in black participants was 2.2%, which is equivalent to 55 per 10000 people per year. The rates were 1.2% per 4 years (30 per 10000 per year) in those aged 40-49 years rising to 4.2% (105 per 10000 per year) at ages 70 years or more.

2.6 Screening for COAG

Glaucoma has long been regarded as a disease that fits well the criteria for screening; it has a long asymptomatic period; it is highly prevalent in the population and early treatment is probably more effective at preventing significant loss of vision (Tielsch, 1996). In 2006 there were no formal glaucoma screening programmes with defined 'at risk' target populations in existence in any country as indicated by Hatt et al. (2006). A recent review of the literature reflects no change in this situation. However, a number of ad hoc strategies exist in some parts of developed countries. In the United States of America (USA), the American Academy of Ophthalmologists (AAO) recommends screening in high risk groups as well as healthy adults, and more regularly as they grow older (AAO, 2005).

In the UK, the International Glaucoma Association (IGA) has made similar recommendations. Free sight tests are offered to persons over 40 years of age where there is a family history of glaucoma. However, this does not present a formal attempt to reach and test everyone at risk in the UK. It is perhaps better termed as opportunistic surveillance rather than screening (Wormald and Rauf, 1995). The British College of Optometrists provided guidelines on which tests should be used and when, but these tests are not enforced. According to the NICE guideline (2009), using screening criteria consisting of an IOP > 21mmHg and a vertical cup-disc ratio of > 0.4, only 60-70% of potential COAG patients will be identified. Until more accurate methods of mass screening are available, screening should be selective but thorough and should include visual field examination (Kanski and Salmon, 2003).

In summary, the current evidence suggests that screening tests can achieve high detection rates (sensitivity) approximately up to 80% according to Harper and Reeves (2000), but the false positive rates (this is the proportion of people without the disease with positive test results) are typically as high as 10-30%. This means that about 10-30% of all people tested would be referred for further examination that adds more burdens on overstretched services (Fraser et al., 2001). Furthermore, Vernon (2011) observed that if the NICE glaucoma screening guidance is followed, it is predicted that more people with suspect of COAG will be referred from primary care for management; more people will have optic disc imaging, and so more people will be treated for glaucoma and have surgery for the condition.

In most Western societies, population screening for COAG is probably unjustified as there is no satisfactory screening test that has been identified as suitable for mass screening. Furthermore, the prevalence of COAG is generally low, so the yield from the screening will also be low which could be particularly tackled by restricting the screening to vulnerable groups, such as elderly or people with strong family history, and particularly those who are socially deprived. Finally, further evidence is required to establish a strong relationship between starting early treatment and a reduction of visual disability or impairment as current evidence suggests that treatment delays the deterioration of visual field by approximately 18 months only (Heijl et al, 2002).

The uptake of testing by the British population is variable and the less educated and more deprived communities and ethnic minorities are less likely to seek testing (Fraser et al., 2001). Given the higher rates of COAG amongst Afro-Caribbeans for instance, collaborative educational programmes that raise awareness of the condition and target the high-risk groups could be the way forward for glaucoma screening. Improving patients and families understanding of the risks and hereditary element of glaucoma is also another way to increase the uptake of screening.

2.7 Coping with COAG and Quality of Life

The relationship between glaucoma as a disease and the experience of people who have been diagnosed with glaucoma provides a classic example of a potential gulf between 'medical' and 'social' models of care (Green et al, 2002). The WHO (2001) is advocating for an integrated 'biopsychosocial' model that applies to all people universally. In glaucoma, Levine (1987) observed the focus on the Quality of Life (QoL) of patients as a potential development that implies the merging of biomedical and socio-cultural paradigms with a shared scientific interest in evaluating care. Indeed, this concept directs more attention to the more complete social and psychological wellbeing of individuals and the relationships with others (Leplege and Hunt, 1997). This increased attention to QoL in health care over the past two decades has been greatly facilitated by a generation of user-friendly instruments to measure patient-reported health status and related aspects of QoL (Hunt, 1997). The goal in this section is not to attempt a comprehensive overview of QoL, but to outline selected issues that are of relevance to COAG.

Searching the literature has identified a number of well-documented tools that have been used to assess the subjective status of glaucoma patients. These tools are classified as generic instruments (SF-36, SIP), vision specific instruments (VF-14, NEI-VFQ, NEI-VFQ-25, and ADVS) and glaucoma specific instruments (GSS, COMTOL, GQL, and SIG).

QoL is quite hard to define, and the impact of COAG on QoL is even harder to define (Aspinall et al., 2008). Nonetheless, the ultimate goal in glaucoma management is the maintenance of patients' QoL through the preservation of vision. Therefore, an understanding of how COAG impacts on an individual is that QoL is central to its management (Goldberg et al., 2009).

COAG usually results in visual field defects in the individual's peripheral and occasionally central vision. Following the diagnosis, patients usually spend the rest of their lives attending an eye hospital and taking ocular anti-hypertensive drops on a daily basis. This could have a significant impact on their QoL for several reasons; firstly the diagnosis itself; as some people readily accept the diagnosis and are keen to seek information (Hartmann and Rhee, 2006). Others might find it hard to accept the diagnosis and disappear into the community only to return years later with a substantial deterioration in their visual function, whilst the majority fall in between the two extremes (Severn et al., 2008). Secondly, the treatment of glaucoma that aims at decreasing IOP comes with many problems. The inconvenience of instilling one or more eye drops for the remainder of the individual's life, the experienced side effects that discourage patients from instilling the eye drops, and the cost of the treatment (Nordmann et al., 2003). Lastly, the insidious loss of vision and independence, given that regular hospital outpatient appointment reviews will be required. This could be of major concern for patients with COAG; particularly the elderly (Lester and Zingirian, 2002).

Having said this, the impact of COAG, like the disease itself, comes on very slowly over a period of 10 or 20 years and is usually associated with other medical conditions which make it even harder to know the cause of a specific symptom (Severn et al., 2008). Therefore getting an accurate account from a glaucoma patient about the impact of the disease may not always be easy. However, there are areas that could be potentially affected as a consequence of the disease which include impact on walking, reading and driving.

2.7.1 Walking, Balance and Falling

This is an important aspect of daily living that can be greatly affected by glaucoma. Vision is very important in maintaining balance, and studies have examined this connection by looking at how much individuals sway when they are standing still. Shabana et al (2005) found that glaucoma patients tend to sway a lot more than people with healthy eyes. It comes as no surprise that several studies have found that glaucoma patients tend to fall two to three times more frequently than individuals without glaucoma (Hassan et al., 2007). Unfortunately, once a glaucoma patient reaches this level of difficulty, activities will have to be restricted to the minimum, or to consider using a walking aid that often marks him/her as disabled. This also could greatly impact on a glaucoma patient's quality of life and sense of independence and make him/her rely greatly on the help of others to perform their daily activities (Black et al., 2008). With fewer numbers of patients who have personal transport, surely, this adds complexity for the glaucoma patient who now has to rely on public transport to get him/her to a clinic appointment. Therefore, this research may have a profound effect on maintaining an ability to get around and overall quality of life.

2.7.2 Impact on Reading

Reading as a task primarily involves central vision. However, a study that looked at reading difficulties amongst glaucoma patients found that many people with glaucoma express difficulty in finding the next line (Viswanathan et al., 1999). This means that it may be glaucoma patients have no problem seeing what is in front of them, but to scan a page or search for specific information becomes difficult. Few studies exist that look at glaucoma patients who give up reading, although it is one of the most important vision-related activities and likely to have a huge impact on a patient's QoL (Aspinall et al., 2008).

2.7.3 Impact on Driving Ability

Loss of peripheral vision will considerably undermine the ability to drive. Haymes et al. (2008) argued that relatively early glaucoma can make it difficult to see pedestrians on the road, while more advanced disease can infringe on central vision, with obvious consequences. Other studies suggested even healthier eyes with a great amount of visual field loss was associated with worsening driving outcomes (Szlyk et al., 2002). Patients handle the issue of driving differently. Some will express the difficulties faced when driving and having more frequent accidents; some will manage to continue to drive safely, while others will cut back on driving or stop driving altogether (McGwin et al., 2005). This can have a great effect on the individual's QoL especially with the elderly who sometimes have no one else to rely on for help getting to the shops, socialise or even attending their outpatient clinic appointments. It may have an even greater effect in cases where the patient is a taxi driver and supports his or her entire family and has to give up his or her driving or risk his or her life and that of others. There are legal guidelines in place to prevent patients who have lost more than half of the visual field in both eyes; all of this makes the impact of glaucoma on driving sometimes devastating (Freeman, et al., 2006).

Section II: Meta-analysis of Self-Management Programmes in Chronic Conditions

Meta-analysis is a scientific tool that can be used to summarise, appraise and communicate the results and implications of otherwise unmanageable quantities of research. It is of particular value in bringing together a number of separately conducted studies, sometimes with conflicting findings, and synthesise their results (CRD, 2001).

In health care, with a constantly expanding amount of research and data to be considered by health professionals, Meta-analysis and systematic reviews become valuable tools for professionals who want to keep up with new evidence, gathering and synthesising evidence from reliable research to facilitate incorporation of research into practice (Higgins & Green, 2005). In the existence of uncertainty regarding the potential benefits or harm of certain new technologies or practices, meta-analysis and systematic reviews are of particular value in bringing together a number of separately conducted studies. They are essential to identify areas where the existing literature is insufficient, where gaps have arisen, and where further research is required (Kitchenham, 2004).

Systematic reviews may or may not include a statistical synthesis of the results from independent studies which is what meta-analysis does. The Cochrane Collaboration (2006) defined meta-analysis as the statistical combination of results from two or more separate studies, which generally aims to produce a single estimate of a treatment effect.

The Cochrane Collaboration (2006) identifies three main reasons for undertaking a meta-analysis in a review.

- To increase power and the chance the researcher can detect a real effect as statistically significant if it exists.
- To improve precision of researcher estimation of treatment effect observed.
- To answer questions not presented by individual studies to settle controversies arising from conflicting studies to generate new hypotheses.

2.8 Rationale for undertaking a meta-analysis:

Undertaking this meta-analysis involved taking the findings from several randomised controlled trials of self-management programmes for patients with chronic diseases and analysing those using standardized statistical procedures. This helps to draw conclusions and detect patterns and relationships between findings which will enhance the precision of estimates of treatment effects, leading to reduced probability of false negative results, and potentially to a more timely introduction of effective treatments (Polit & Beck, 2006).

Unlike traditional reviews, the purpose of this meta-analysis is to provide as complete a list as possible of all the published and unpublished studies relating to chronic diseases self-management. While traditional reviews attempt to summarize results of a number of studies, meta-analysis uses explicit and rigorous criteria to identify, critically evaluate and synthesize all the literature on a particular topic. It would reveal a new view of the efficacy self-management programmes.

2.9 Formulation of Review Question

One of the most critical issues in any meta-analysis is to formulate the right question that is focused, measurable and clear. Kitchenham (2004) pointed out that the right question in systematic reviews is one that is meaningful and important to practitioners as well as researchers. It should also lead to change in current practice or to increase confidence in the value of current practice, and identify discrepancies between commonly held beliefs and realities.

In addition, a good understanding of the research question will guide the reviewer in choosing the right studies to be included as well as the data required to answer the question (Jackson & Waters, 2004a). The formulated questions of this analysis are:

- Do different ways of involving patients with chronic conditions in the planning and implementation of health services succeed in improving the quality of health care services?
- Do interventions that include empowering and enabling activities in their training programmes succeed in increasing people's awareness and readiness to

assume more responsibilities regarding their own health and wellbeing as well as health care services they receive?

2.10 Identification of Studies

The aim of meta-analysis is to find as many primary studies relevant to the research question as possible using an unbiased search strategy (Kitchenham, 2004). For this analysis, all randomised controlled trials that examine interventions that involved expert patients with chronic arthritis and aimed at improving their self-management skills as well as the services they receiving were identified.

Randomised controlled trials (RCTs) are considered by many in the biomedical model to be the gold standard when addressing questions regarding effectiveness in healthcare; whereas other study designs are appropriate for addressing other types of questions (CRD, 2001). Researchers should consider what study designs are likely to provide reliable data with which to answer their questions. Because this analysis addresses questions about the effects of health care intervention from a biomedical perspective, it focuses primarily on RCTs. Many researchers in the medical field argue that there are two reasons why caution should be exercised in relation to including non-randomised studies in an analysis of the effects of health care. Both relate to bias. First, although it is possible to control for confounders that are known and measured using other study designs, randomisation is the only way to control confounders that are not known or not measured (Kunz & Oxman, 1998). Empirical evidence suggests that, on average, non-randomised studies tend to overestimate the effects of healthcare (Schulz, et al., 1995). However, a systematic methodology review has shown that the extent and even the direction of bias in non-randomised studies are often impossible to predict (Kunz & Oxman, 1998).

Second, although it is often difficult to locate RCTs and reviews that fail to include unpublished trials, they may be biased toward overestimating the effectiveness of an intervention (Dickersin, et al., 1994). Consequently, researchers in the biomedical model believe including studies other than controlled trials in an analysis may require additional efforts to identify studies and to keep the analysis up-to-date. This might increase the risk that the results of the analysis will be influenced by publication bias.

2.10.1 Types of participants:

This analysis included adult participants. Although it was intended to divide participants into age subgroups of adults, adolescents and children, only studies involving adults are included as studies involving the other subgroups are not assessable in published literature.

Studies which target participants without an established chronic rheumatoid arthritis and/or chronic osteoarthritis that have been clinically confirmed have been excluded. Studies that target patients with compromised mentation, cancer patients who received chemotherapy, radiotherapy or any other therapeutic operation in the last year have also been excluded.

2.10.2 Types of intervention:

This analysis includes lay-led self-management education programmes for people with chronic arthritis. Interventions of interest are self management education programmes for people with chronic conditions. For the purpose of this analysis, these interventions are defined as structured programmes for people with chronic conditions which are judged to be primarily educational and address self-management of disease and where the majority of the course content was delivered by lay people. If health professionals participated as leaders they would have had a chronic illness and they would have adhered to the course manual. In addition, face to face education, in a group or as individuals have been included.

Likely components of self-management programmes are:

- Prior training of lay tutors if appropriate
- Education about the disease or condition
- Education about lifestyle
- Education on how to manage the condition and its symptoms
- Skills training
- Problem solving techniques
- Self management-techniques

Interventions that are for people without established chronic conditions, for example, programmes that target people at higher risk of developing arthritis to encourage them to exercise were excluded.

2.10.3 Types of outcome measures:

Two main outcomes were identified, one primary and the other secondary. The Primary outcomes of the analysis are:

- *Health status*: including patient self-rating quality of life, disability, pain, fatigue, psychological well-being.
- *Health behaviour*: including exercise, cognitive symptoms management, and adherence.
- *Clinical improvement* in examination findings as judged by observers,
- *Healthcare use*: including doctors' visits, outpatient doctor visits, emergency room visits, hospital admissions and length of stay.
- *Self-care and self-efficacy*: represents a person's confidence to carry out self-management behaviour.

The Secondary outcomes are:

- Knowledge of the condition
- Change in clinical exam findings
- Quality of life measures
- Communication with professionals
- Cost of delivering programmes.

2.10.4 Search strategies and studies identification

It was necessary to determine and follow a search strategy that started with a preliminary search which aimed to identify existing reviews and assess the volume of potentially relevant studies. This therefore required identifying the search terms and key words that will give the maximum number of relevant studies (CRD, 2001). In this review the following electronic databases were searched.

- Cochrane Central Register of Controlled Trials (CENTRAL) from inception;

- MEDLINE from 1997;
- EMBASE from 1997;
- AMED from 1997;
- CINHAL from 1997;
- Database of abstracts of reviews of effects (DARE) from inception;
- National Research Register from inception;
- NHS Economic Evaluation Database;
- ProQuest from conception.

Search strategies included MeSH and text word terms as appropriate. Table (2.4) illustrates the search terms that were used to search electronic databases and relevant journal articles and reports.

Table (2.4): Search Terms

Population	Problem area	Promotion topic	Intervention	type of study
Patient$	Arthritis	Self care	Patient education	Randomised controlled trials
Consumer$	Rheumatoid arthritis	Self efficacy	Enabling	Random allocation
Client$	Osteoarthritis	Self manage$	Empower$	Double blinded method
Lay	Long term			Clin$ trial$
Volunteer$	Chronic disease	Self monitoring	Health information	Single blind method
Train$	Degenerative disease	Self help	Practice guidline$	Clinical trials
Expert patient$	Ongoing health condition	Self-efficacy	Health priority$	Compare$ Comparative study
Instruct$	Persistent illness$ or disease$		Health educat$	Single or double or treble or triple blind$
Skill$	Long term illness$ or disease$			Effective$
Expert$				Evaluat$

2.10.5 Consulting experts:

Consulting experts in the field was helpful to identify relevant articles and ongoing reviews. For example, Cochrane Vision and Eye Collaboration were contacted for guidance regarding guidelines to follow in the effectiveness of systematic reviews. Subject librarians were contacted to formulate the research terms to be used.

Reference lists of retrieved articles and published reviews on the topic were searched. Appropriate journals were also hand searched. The reference lists of included studies for any additional studies not identified through electronic search were considered. Experts in the field for information on current, past or unpublished trials and relevant studies were also consulted.

2.11 Methods of the Meta-analysis

2.11.1 Assessment of search results:

Potential studies that may possibly fit the "inclusion criteria" as defined in this protocol were assessed. Where a decision was made to include a potential study a full copy was obtained for further scrutiny. If any doubt arose on the eligibility of a study for inclusion, consultation with supervisors was sought to assist in decision-making.

2.11.2 Data extraction and management:

A data extraction form using some examples of eligible studies was developed. Data from all eligible studies were extracted independently.

2.11.3 Assessment of methodological quality:

The quality of reporting of each randomised trial was assessed mainly according to the quality criteria specified by Schulz, et al. (1995) and Jadad, et al. (1996). The following criteria were examined:

1. Minimisation of selection bias:

-Adequate randomisation procedure

-Adequate concealment allocation.

2. Minimisation of attrition bias:

-Complete description of withdrawals/dropouts.

-Intention-to-treat participants.

3. Minimisation of detection bias:

-Outcome assessor blinded to the intervention.

According to these criteria, trials were classified into three categories to inform sensitivity analysis.

(A) All quality criteria met: low risk of bias.
(B) One or more of the quality criteria partly met: moderate risk of bias.
(C) One or more criteria not met: high risk of bias.

2.11.4 Confounders within the groups:

-Baseline health status (presence of other infections, conditions)

-Gender

-Age

-Disease type

The nature of self-management interventions may mean that different interventions or intervention components can be aggregated together. In order to evaluate effectiveness by specific intervention designs, interventions were classified carefully and sensitivity analysis was conducted to examine the following design factors:

-Duration of interventions (how many sessions per week)

-Setting of intervention (school, community, clinical, urban)

-Lay or professional led interventions (level of training of lay)

-Quality of volunteers' training (amount, type)

-Individual versus group intervention

-Type of intervention (support versus counselling, education versus training).

2.11.5 Consumer involvement:

The involvement of consumers, who are affected by the conditions listed above, or those who designed and administered interventions, was of central importance in this review. Self-management intervention is a complex concept that has diverse meanings that are dependent on the context within which it is used.

2.12 Data collection:

Studies for inclusion in this analysis were independently extracted onto data extraction forms that included study methods, participants, interventions, outcomes, and adverse events. Any further data not included in these fields were extracted in specially designed section called "Notes". Over all data extracted were presented in table format.

2.12.1 Data Synthesis:

It is anticipated that the included studies have used different rating scales. The validity and reliability of each rating scale as supported by previous studies were assessed. However, the aim was to summarise data from studies collecting similar outcomes and using similar follow-up times. The heterogeneity of the interventions, the follow-up periods and the outcomes observed in the trials did not allow for statistical combinations of the study results.

2.12.2 Table of included studies:

Tables of the included and excluded studies were synthesised. Within each of these sets of tables, interventions were further grouped according to type of study, type of intervention and participant characteristics. Subgroup and sensitivity were conducted to examine the effects of specific factors. For example:

1. Method of support: group, individual, online, telephone.
2. Different chronic conditions.
3. Differences in effect across socioeconomic strata and health equity. These were assessed by evaluating whether self-management interventions reduce health inequalities. Possible categories for defining socioeconomic disadvantages were considered:
    - Race/ethnicity/culture
    - Gender
    - Socioeconomic status
    - Occupation, if appropriate.

Interventions were classified as:

1) Effective: interventions were considered effective for reducing inequalities in health if the improvements reported were greater for people from disadvantaged groups.
2) Potentially effective: interventions were delivered only to people from disadvantaged groups, and show statistically significant and meaningful positive effects.
3) Not effective: interventions resulted in improvements for people in advantaged groups but not for those in disadvantaged groups.
4) Uncertain: intervention evidence is mixed or equally effective for people from both advantaged and disadvantaged groups.

This analysis was subjected to the amount of information collected and provided by the authors. If sufficient demographic data were not available to address issues of inequalities then this was acknowledged.

2.13 Description of studies

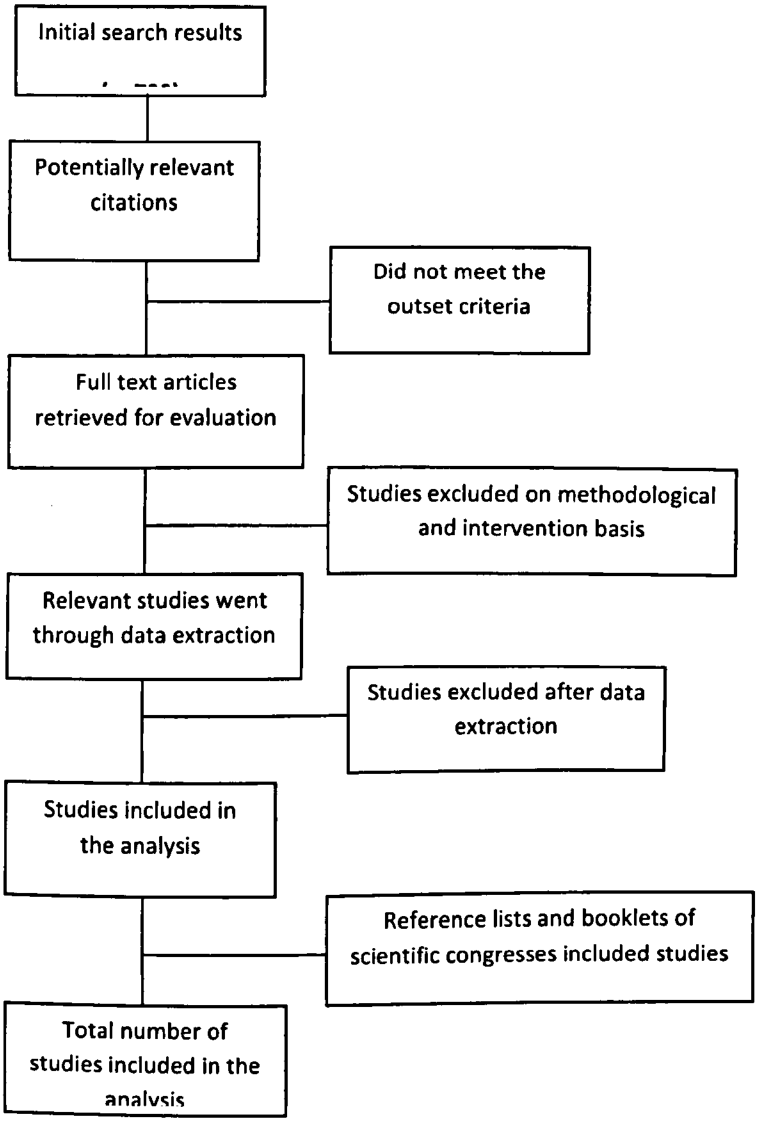
This section collates the findings of studies included in this analysis in a structured way. It presents information about the studies characteristics (population, sample, interventions and outcomes), their design, quality and their effects to provide a deeper understanding of the evidence.

2.13.1 Finding the studies

The initial search yielded 700 references and abstracts, of which only 146 publications were found to be relevant because they included evaluative elements. The rest of the publications examined self-management programmes which were delivered by health professionals mainly and/or addressed other chronic conditions like asthma, diabetes, depression and heart failure. Amongst the 146 references, 53 studies required retrieval of the full article for scrutiny. Only 23 studies went through the data extraction phase, of which 18 studies were later excluded for methodological reasons, as they lacked a clear evaluation of the whole experience of patient participation in the programme. Checking reference lists revealed a further four relevant articles, and checking the reference lists of these revealed a further relevant article. By examining booklets of the scientific congresses in the field of arthritis a further five potentially relevant articles were identified and obtained as full text copies, of which one study was included.

Therefore, the total number of primary studies that were included was 6 as illustrated in figure (2.3).

Figure (2.3): Studies selection



2.13.2 Included Studies

Six trials were included in this review. These were studies published by Lorig, et al. (1999a); Lorig, et al. (1999b); Barlow, et al. (2000); Dongbo, et al. (2003); Buszewicz, et al. (2006) and Kennedy, et al. (2007) (refer to appendix 1 for full details of the included studies). These are summarised below and details are provided in the 'characteristics of included studies' Table (2.5) by its country and study design.

Table (2.5): Characteristics of studies included

Author, year	Study design characteristics	Country
Lorig, et al. (1999a)	**Randomised controlled study**	United States of America
Lorig, et al. (1999b)	**Randomised controlled study**	United States of America
Barlow, et al. (2000)	**Randomised controlled study**	United Kingdom
Dongbo, et al. (2003)	**Randomised controlled study**	China
Buszewicz, et al. (2006)	**Randomised controlled study**	United Kingdom
Kennedy, et al. (2007)	**Randomised controlled study**	United Kingdom

Lorig, et al. (1999a) in a four-month trial followed by one year health-related outcome study, conducted a six week lay-led self-management arthritis programme for Spanish speaking participants. They tried to determine the role of self-efficacy in predicting health status for this population. In an attempt to reach Spanish speaking communities in which arthritis is the leading cause of disability, the Spanish Arthritis Self-Management Programme (SASMP) was developed and evaluated as a first step toward remedying this problem.

Lorig, et al. (1999b) in a six-month lay-led trial, based in northern California, examined the effectiveness of Chronic Disease Self-Management Programmes (CDSMP) designed for use amongst heterogeneous groups. They went further to explore the differential effectiveness of the intervention for subjects with specific diseases and comorbidities. All patients with a chronic condition were eligible to be included apart from patients with compromised mentation, cancer patients and persons younger than 40 years of age. To ensure optimal responsiveness of the programme, Lorig and her team conducted two needs assessments through focus groups and based the content and methodology of CDSMP on the subject's particular needs. To measure effectiveness Lorig and colleagues used the Mental Health Inventory 5 Scale (MHI-5), Quality of Life Short Form (SF-20) and Pain scale as outcome measures for success.

Barlow, et al. (2000) examined the effectiveness of the Arthritis Self-Management Programme (ASMP) when delivered amongst UK participants in a pragmatic, randomised, controlled trial. Lorig et al's arthritis handbook and ASMP were implemented and delivered by lay volunteers who have arthritis. All patients with chronic arthritis who were over the age of 18 years and able to complete questionnaires were eligible for inclusion.

Dongbo, et al. (2003) in a randomised controlled trial, evaluated the effectiveness of a CDSMP based on five urban communities in Shanghai which have the heaviest burden of non-communicable diseases and the largest ageing population in China. Although Lorig's CDSMP was widely accepted and implemented in this research, there are parts which were deemed culturally inappropriate and replaced with culturally-oriented components. Dongbo et al went further to design a Chinese culturally acceptable CDSMP and train lay-volunteers to deliver the programme. Patients less than 20 years of age and those with compromised mentation and cancer patients who were receiving treatment were excluded as well as patients for whom problems could be expected with compliance or follow up. This is a large scale trial that was published in English and French languages as well as Spanish. The study has not accounted for withdrawals and dropouts; neither the participants nor the data were blinded to the treatment assignment.

Buszewicz, et al. (2006) conducted a randomised controlled trial to evaluate the clinical effectiveness of a Self-Management Programme for patients with arthritis amongst 74 general Primary Care Practices in the UK. Teaching sessions were based on self-efficacy theory and delivered by lay volunteers as well as health professionals. The research team used well established and validated clinical measures including the Quality of Life Scale (SF36), Arthritis Scale (WOMAC), Hospital Anxiety and Depression (HAD) Scale and Arthritis Self-efficacy Scale. Subjects' details were blinded to the research team apart from the trial manager and dropouts were accounted for.

Kennedy et al. (2007) in a two-arm trial compared the clinical and cost effectiveness of a lay-led self care support programme amongst patients with a chronic condition in community settings in England. This trial was conducted in parallel with a wider national implementation of EPP to explicitly model the relationship between cost and outcome. A nationwide recruitment programme was conducted in all 28 strategic health authorities in England, using no specific inclusion or exclusion criteria, beyond a self-defined long-term condition. An anglicised version of Lorig et al's CDSMP was developed based on the theoretical model of social learning, and delivered by a trained pair of lay trainer or volunteer tutors. The team identified self-efficacy, reported energy and routine health service utilisation as primary outcomes with a cost-effectiveness analysis conducted alongside the trial. Kennedy et al took account of dropouts and concealed for allocation.

2.13.2.1 Study population

The characteristics of study populations are summarised in Table (2.6). Only studies of adults were included because in childhood and adolescence these illnesses are quite uncommon and only studies addressing this population were found.

Table (2.6): Characteristics of the study population by age and gender
Key: I= Intervention group, C= Control group, M= Male, F= Female

Author (Year)	**I. Age (mean)**	C. Age (mean)	**I. Gender (%)**	C. Gender (%)
Lorig, et al. (1999a)	**62.5 years**	62.5 years	**15% M, 85% F**	19% M, 81% F
Lorig, et al. (1999b)	**65.5 years**	65 years	**35% M, 75% F**	36% M, 74% F
Barlow, et al. (2000)	**57.3 years**	59.1 years	**15% M, 85% F**	17% M, 73% F
Dongbo, et al. (2003)	**64.21 years**	63.8 years	**26.7%M,73.3%F**	30.9%M, 69.1% F
Buszewicz, et al (2006)	**68.4 years**	68.7 years	**37% M, 63% F**	37% M, 67% F
Kennedy, et al. (2007)	**55.5 years**	55.3 years	**30% M, 70% F**	30.4% M, 69.6%F

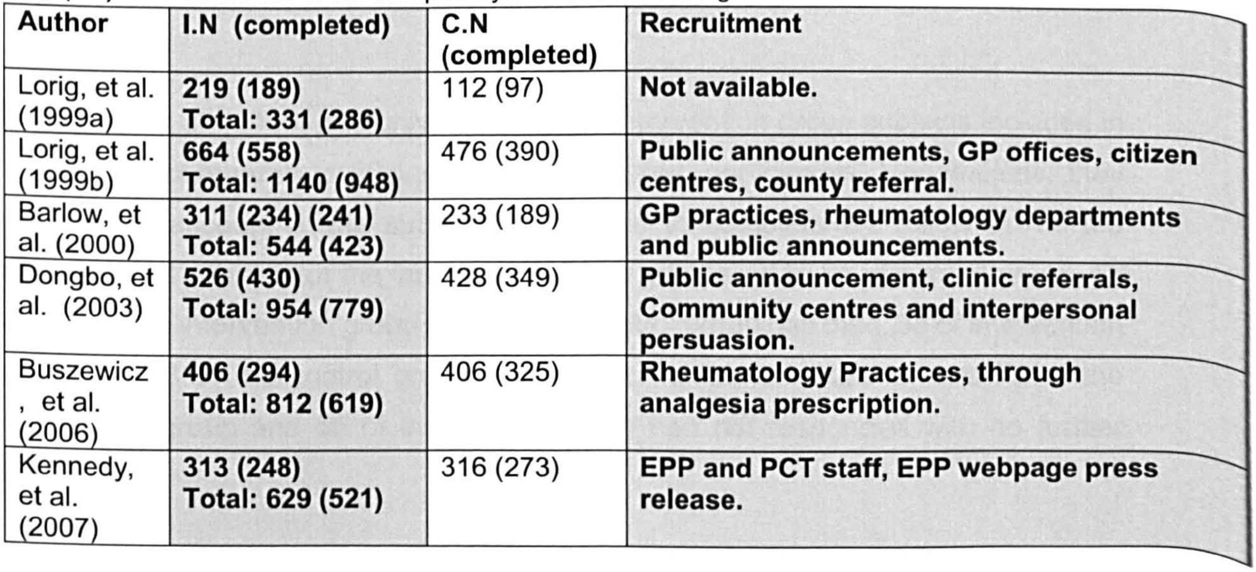
In addition, they create additional issues for self-management interventions, such as parent-child relationships, child development, puberty and education, which are beyond the scope of this review. This review is limited to randomised trials published between 1998 and 2008 to capture the content and effectiveness of fairly recent interventions.

All studies targeted adult people with an average age of 55.5 to 68.4 years of age in the treatment group compared to 55.3 to 68.7 years of age in the control group. Both men and women were targeted equally in all studies, however, although the messages were basically designed to target both men and women equally, all the studies included have significantly less male participants than females for reasons, which will be discussed later. Nonetheless, there was no significant difference between the percentage of male and female participants when comparing treatment and control group populations in each study.

2.13.2.2 Sample and Withdrawals

A total of 4410 participants were included in the 6 trials with 2439 (55.3%) in the intervention group. The number of participants recruited varied widely from the smallest study (Lorig, et al., 1999a) that included 331 participants with 219 (66%) allocated to the intervention group compared to the largest study (Lorig, et al., 1999b), which included 1140 participants with 664 (58%) randomised to the intervention group. Comparability of different types of interventions is likely to be affected by the greater power of the larger studies to detect significant effects compared with smaller studies. The following table (2.7) describes the characteristics of studies included with their samples and recruitment procedure.

Table (2.7): Characteristics of the Samples by Recruitment Setting



Author	**I.N (completed)**	**C.N (completed)**	**Recruitment**
Lorig, et al. (1999a)	**219 (189)** **Total: 331 (286)**	112 (97)	**Not available.**
Lorig, et al. (1999b)	**664 (558)** **Total: 1140 (948)**	476 (390)	**Public announcements, GP offices, citizen centres, county referral.**
Barlow, et al. (2000)	**311 (234) (241)** **Total: 544 (423)**	233 (189)	**GP practices, rheumatology departments and public announcements.**
Dongbo, et al. (2003)	**526 (430)** **Total: 954 (779)**	428 (349)	**Public announcement, clinic referrals, Community centres and interpersonal persuasion.**
Buszewicz , et al. (2006)	**406 (294)** **Total: 812 (619)**	406 (325)	**Rheumatology Practices, through analgesia prescription.**
Kennedy, et al. (2007)	**313 (248)** **Total: 629 (521)**	316 (273)	**EPP and PCT staff, EPP webpage press release.**

Egger, et al. (1997) stated that loss to follow up withdrawal subjects may lead to the exclusion of patients after they have been allocated to treatment groups, which may introduce attrition bias. Lorig, et al. (1999a) study shows 86% of the intervention group completed the 4-month follow up compared to the same percentage of 86% in the control group. Lorig, et al. (1999b) trial shows 84% of the intervention group and 83% of control group completed the 6-month data collection period. However, Lorig et al. took full account of the (treatment-control) subjects not completing the final 6-month data collection, 1.2% - 0.8% had died, 3.4% -7.8% were too ill to continue, and 11.4% - 9.4% had unknown reasons for withdrawal. Barlow, et al. (2000) trial has 77.5% of the intervention group compared to 81.1% of control group completing the 4-month follow up, with no account mentioned for the participants who failed to complete the follow up.

Dongbo, et al. (2003) study has an almost equal percentage of participants in the groups who completed the follow up, with 81.7% of the intervention group and 81.5% of the control group completing the study. Taking a full account of subjects who failed to complete follow up, this trial has provided a good example of handling the loss to follow up. In total, 56 subjects in the intervention group and 69 participants in the control group were identified. Of which 12 of the intervention group and 17 of the control group moved out of the area, 5of the intervention group and 10 of the control group were too ill to complete, 12 of the intervention group and 17 of control group refused to continue, 4 of the intervention group and 7 of the control group had died and 23 of the intervention group and 18 of the control group had an unknown reason to withdraw.

Buszewicz, et al. (2006) had only 72.5% of the intervention group subjects included in the analysis compared to 80% of the control group participants. Nonetheless, they provided an account of the subjects who failed to complete the follow up as the following; 112 subjects of the intervention group compared to 81 of control group. Of which 5 of the intervention group and 2 of the control group had died, 35 of intervention group and 23 of the control group withdrew for unknown reasons, and 72 of the intervention group and 56 of the control group had not responded with no further details given.

Kennedy, et al. (2007) had a differential attrition of 79.2% of the intervention group subjects completed the 6-month follow up sessions compared to 86.4% of the control group subjects who completed the same follow up. However, Kennedy, et al. (2007) could not provide a clear account of subjects who decided to withdraw.

2.13.2.3. Participation rates and Follow up

The time demand of self-management interventions could result in low participation and high rates of attrition. Analysis of participation rates is difficult because many studies fail to report them. However, knowledge of participation is important since it indicates the extent to which results can be generalised. All studies included in this analysis showed significantly high participation rates ranging from 72.5% to 86.4%. When comparing the participation rates of the intervention groups to the control groups across studies there is an insignificant difference. As previously noticed, self-management interventions with greater intensity and longer duration had high attrition rates. The following table (2.8) describes the characteristics of the studies according to the duration of intervention and follow up as well as their participation rate.

Table (2.8): Characteristics of duration of interventions and follow up

Author (Year)	Duration	Follow-up	Participation rate
Lorig, et al. (1999a)	**Six weekly of 2 hour sessions**	4 months & 1year	I (86%), C (86%).
Lorig, et al. (1999b)	**Seven weekly 2.5 hour sessions**	6 months	I (84%), C (82%).
Barlow, et al. (2000)	**Six 2hour sessions**	4 months	I (77.5%), C (81.1%)
Dongbo, et al. (2003)	**Seven 2-2.5 hours sessions**	6 months	I (81.7%), C (81.5%)
Buszewicz, et al(2006)	**Six sessions**	1, 4 & 12 months	I (72.5%), C (80%)
Kennedy, et al. (2007)	**Six 2.5hour sessions**	6 months	I (79.2%), C (86.4%)

Key: **I**=intervention group, **C**=Control group.

Buszewicz, et al. (2006) study has the longest duration of intervention of 12 months in comparison to the other studies and it is evident that it has the lowest participation rate and the greatest difference between the intervention and control group. The factors leading to high attrition are clearly complex, but characteristics of individuals most likely to drop out should also be investigated to ensure the interventions are targeted most effectively.

2.13.2.4. Delivery

All of the self-management interventions were delivered in a group setting. The arguments for using group intervention include reduced costs and the potential value of group learning. Individual interventions are often justified on the basis that the intervention can be tailored to individual needs, and they might be easier to integrate into clinical practice. Evidence on the effectiveness of group or individual delivery is scarce because comparisons across studies are confounded by many other variables.

For example, Lorig, et al. (1999b) study, in order to assure the programme would be easily accessible to patients; it was held in multiple community sites including churches, senior and community centres, public libraries and health care facilities. For the convenience of patients, interventions were planned at varied times including late mornings, early afternoons, evenings as well as weekends. On the other hand, Dongbo, et al. (2003) considered the different local features of the five communities included in their study and accordingly adopted two delivery models. The first was a "commonly participatory model" in which communities were working alongside professionals and stakeholders in every step of the planning and implementation. The second was a "professional dominated model" where communities provided passive support to the programme. Kennedy, et al. (2007) interventions were delivered in non-NHS premises while the other two studies Barlow, et al. (2000) and Buszewicz, et al. (2006 lacked a clear mode of delivery.

There is research evidence that positive role model "lay leaders" with similar backgrounds and disease problems increase patients' self-efficacy or confidence in their ability to manage their disease (Lorig, et al., 1999a). All the included studies with the exception of Buszewicz, et al. (2006) clearly identified the leaders who delivered the intervention. Lay leaders have the benefit of acting as role models and being less costly, but health care professionals are more able to address factual issues related to illness. Presently, little evidence suggests which approach is more effective. Two studies that made direct comparisons between lay-led and professional-led programmes showed no improvement in pain or disability with either approach but showed differential changes in other outcomes (Lorig, et al., 1986). There is also insufficient evidence to show whether certain groups or professions are better placed to deliver self-management programmes. Nonetheless, training is an important determinant of effectiveness, particularly when complex skills such as cognitive behavioural techniques are used. Information about training of course leaders was not commonly reported as illustrated in table (2.9).

Table (2.9): Characteristic of Interventions Delivery by the Deliverer

Author (Year)	Individual	Delivered by
Lorig, et al. (1999a)	**Group**	Limited information.
Lorig, et al. (1999b)	**Group**	Trained lay leaders (71%), students (15%) and (23%) health professional.
Barlow, et al. (2000)	**Group**	Lay leaders who suffer arthritis.
Dongbo, et al. (2003)	**Group**	Trained non-health professional volunteer leaders.
Buszewicz, et al. (2006)	**Group**	Unclear
Kennedy, et al. (2007)	**Group**	Lay volunteer trainers subject to quality assurance.

2.13.2.5 Characteristics of intervention:

The CDSMP and its anglicised version (the EPP) the Chinese version and the Spanish culturally adapted version all typically consist of a structured course of six (originally seven) weekly sessions lasting around 2 to 2.5 hours led by one or two trained facilitators. The evolution of self-management interventions has accompanied the power shift in health care services. It began as a system in which health care professionals were seen as experts and the patient as a passive recipient of care, to more collaborative care in which expertise is shared between the patient and professional to achieve the best outcomes. This trend has encouraged self-management interventions to change from the provision of information to interventions that address problem solving and coping skills.

In this analysis the intention has been to include interventions that assess the effectiveness of such intervention for chronic illnesses, in particular, the focus on arthritis. This illness has been chosen for many reasons: it has a high and increasing frequency with associated high costs to health services. Arthritis self-management interventions and research are well developed; reviews have revealed at least 100 intervention studies of high quality, and it is possible to examine how the important similarities and differences in the day-to-day management and consequences of arthritis compare with chronic eye conditions like glaucoma.

Six RCTs were identified that address arthritis (rheumatoid arthritis and osteoarthritis), of which three studies Lorig, et al. (1999a); Barlow, et al. (2000); and Buszewicz, et al. (2006) were disease specific. The other three studies have focused on long term conditions with quite broad aims, but with a main focus on reducing pain and improving physical and psychological functioning. However these objectives affect a range of methodological and content issues which will be discussed later in this chapter.

2.13.2.6 Theoretical framework of self-management programmes:

The studies analysed were varied in the extent to which they explicitly stated the theoretical approach on which self-management interventions were based. Sometimes only components of a theory were mentioned (i.e., self-efficacy) without definition of the underlying theory. Interventions fell into two main areas; self-efficacy theory, or an educational model expanded to incorporate other components such as social support, exercise and other skills. The following table (2.10) shows the characteristics of the studies with the topics that were covered in each self-management intervention.

Table (2.10): Characteristics of studies with topics covered.

Author (Year)	**Self-efficacy topic covered.**
Lorig, et al. (1999a)	A culturally adapted format of all topics covered in the original version.
Lorig, et al. (1999b)	Exercise, cognitive symptom management techniques, nutrition, fatigue, sleep management, use of community resources, use of medication, dealing with emotions, communication, problem solving and decision making.
Barlow, et al. (2000)	Information about arthritis, self-management principles, exercise, cognitive symptom management, dealing with emotions, communication and contracting.
Dongbo, et al. (2003)	Exercise, cognitive symptoms management techniques, nutrition, fatigue and sleep management, use of community resources, use of medications, dealing with emotions, communication, problem solving and decision making.
Buszewicz, et al. (2006)	Unclear.
Kennedy, et al. (2007)	Sessions on relaxation, diet, exercise, fatigue, breaking the symptoms cycle, managing pain, managing medication and communication.

Social learning theory (Bandura, 1977) has led the way to the use of problem solving and goal setting to enhance participants' self-efficacy and to encourage health related behaviours such as exercise, diet, joint protection, and techniques for cognitive pain management in arthritis. Other studies focused on a cognitive behavioural approach to target pain and physical function and to improve coping in arthritis. Comparisons of different self-management interventions allow identification of components or approaches that might be more effective than others.

In comparing the six different studies some changes were observed favouring the inclusion of training in coping skills and exercise as a way of reducing pain. This kind of comparison of self-management interventions has great potential for identifying active components and adjusting other components to make it more culture orientated as in the case of Dongbo, et al. (2003).

2.13.2.7 Outcomes and Results

The following table (2.11) presents all the studies by their outcomes assessed. The outcome measures most frequently assessed in these studies were self-report of symptoms. All the studies assessed more than one outcome; in addition, some studies included outcomes that had not been specifically targeted in their programme; which could dilute their overall effectiveness. To accurately assess a self-management intervention, it is important to link the outcomes measured to those targeted for change.

Table (2.11): Characteristics of studies by the outcomes assessed.

Author (Year)	Outcomes assessed
Lorig, et al. (1999a)	Self-management behaviours, disability, depression, self-rated health, pain, self-efficacy and medication use.
Lorig, et al. (1999b)	Health behaviour, health status, health service utilisation.
Barlow, et al. (2000)	Health beliefs, cognitive-behaviour techniques, health status.
Dongbo, et al. (2003)	Health behaviour change, self-efficacy scale, health status and health care utilisation.
Buszewicz, et al (2006) .	Quality of life, symptoms, physical and psychological well-being.
Kennedy, et al. (2007)	Self-efficacy scale, symptoms, health care utilisation.

a. Outcomes of the analysis

All comparisons are reported at up to six-month follow up unless otherwise stated. The outcomes are:

Primary outcomes measured

- **Health behaviours (Arthritis Self Efficacy "ASE")**

Stretching and strengthening exercise (minutes/week)

Aerobic exercise (minutes/week)

Cognitive symptoms management

- **Health status**

Self-rated health

Disability

Dietary habits

Pain/physical discomfort

Psychological well-being

Energy/ Fatigue

Health distress

- **Health service utilisation**

Medical Doctors and Accident and Emergency department visits

Number of hospital stays

Nights in hospital

b. Secondary outcomes measured

Communication with health professionals

Social/role activity limitations

Health care costs.

2.14 Discussion of outcomes

Symptoms and functioning were common outcomes, with more than 40% of the studies showing some improvement in self-reported symptoms, as did a similar proportion for measure of disability. Previous reviews of the same outcomes in arthritis for example have generally reported that self-management interventions have a small but significant short-term effect, although the changes tend not to be maintained in the long term. In these studies, some evidence suggested improvements in pain beyond 6 months, in one study, and for disability, in two studies. A greater effect on pain was identified for osteoarthritis, with four studies reporting some benefit. The reasons for the difference between the two forms of arthritis are unclear. Comparison is complicated because content of interventions tend to differ.

Assessment of psychological wellbeing as an outcome is complicated by selection of participants. Although numbers with depression and anxiety tend to be higher than in the general population, many individuals recruited into self-management programmes might show little evidence of depressed mood or increased anxiety (Buszewicz, et al., 2006). Expectations that these outcomes will improve after a self-management intervention might be unrealistic. 62% of studies that measured psychological wellbeing reported benefits. All of those that used cognitive behavioural programmes and the one that is based on social learning theory recorded improvements in psychological wellbeing.

Quality of life was assessed in only 29% of the studies analysed. Measuring quality of life is complicated by the fact that disease-specific instruments are widely used and their subscales are generally reported under symptoms, function, and psychological wellbeing rather than as a composite measure. For included studies, little effect was recorded for quality of life, which showed that the relationship between self-management programmes and quality of life is still not well understood. The changes in behaviour needed by self-management interventions might constrain quality of life, but the absence of evidence of such deterioration in this analysis suggests that these interventions have no real cost to patients' quality of life. This necessitates the need for further research to understand the complex relationship between self-management programmes and quality of life.

Improvement of self-management behaviours, such as diet and exercise, or more cognitive behaviours, such as effective coping, is a prime focus of these types of interventions, but 50% of included studies did not assess behaviour changes. It seems that these studies assumed that a simple relationship exists between behaviour change and other outcomes, but this is extremely complex. This is illustrated by some studies where behaviour changed in the absence of changes in more clinical and symptomatic measures. Whilst other studies showed changes in clinical and symptomatic measures happened in the absence of behavioural changes. This clearly explains why there is no one to one relationship between behaviour and measures of symptoms and clinical state.

Reduction in the use of health care is one of the possible economic benefits of self-management interventions, and was the most frequently assessed outcome. The studies analysed were less likely to have an immediate effect on use of health care, since control of symptoms to restrict emergency visits was not the focus of these interventions. Nonetheless, improved self-management could change use of health care. Six studies examined such use for arthritis; two found some reduction in visits to health care professionals.

One enduring issue for self-management interventions is the duration of any effect observed. Few included studies assessed outcomes for more than 12 months, and in those that did, many showed that benefits tend not to be retained at long-term follow-up. Expectations of long-term effects from such interventions might be unreasonable because of the short-term nature of many interventions. Therefore, it remains important not only to examine whether people are able to adopt self-management behaviours in the long term, but also to devise techniques that can lead to long-term changes in behaviour.

2.14.1 Methodological Quality of included studies.

Based on the quality criteria described in the analysis methods section above and with particular respect to the context of this analysis, three studies were deemed to be of high methodological quality (Barlow, et al., 2000; Buszewicz, et al., 2006; Kennedy, et al., 2007) where the other three studies appeared to be of intermediate quality (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003).

2.14.2 Method of randomisation:

Four of the six randomised controlled trials included provided adequate description of the way randomisation was conducted (Barlow, et al., 2000; Dongbo, et al., 2003; Buszewicz, et al., 2006; Kennedy, et al., 2007), whilst Lorig, et al. (1999a), and Lorig, et al. (1999b) methods remain unclear.

2.14.2.1 Allocation

The concealment of allocation was adequate in three RCTs (Barlow, et al., 2000; Buszewicz, et al., 2006; Kennedy, et al., 2007). The remaining three randomised controlled trials made no reference to allocation concealment (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003).

2.14.2.2 Blinding

Full blinding of consented study participants to their allocation groups in studies that investigate behavioural changes is not possible, which questions the appropriateness of this criterion when examining interventions that improve participants' communication with health professionals (Vertigan, et al., 2006). Although only three studies described adequate blinding (Lorig, et al., 1999b; Dongbo, et al., 2003; Buszewicz, et al., 2006) the other three trials (Lorig, et al., 1999a; Barlow, et al., 2000; Kennedy, et al., 2007) have collected outcomes by mail questionnaire which minimises the potential risk of blinding.

2.14.2.3 Losses to follow up and withdrawals

Follow up periods varied across included studies from 4 to 6 months with two studies following subjects to 1 year (Lorig, et al., 1999a; Buszewicz, et al., 2006). Losses to follow up information were reported in all included studies. Of those, four studies achieved follow up rates of more than 80% (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003; Kennedy, et al., 2007). While the other two studies have reported follow up rates of more than 70% (Barlow, et al., 2000; Buszewicz, et al., 2006).

2.14.2.4 Intention-to-treat analysis

Only one study reported analysis to be by intention to treat (Barlow, et al., 2000). While Buszewicz, et al. (2006) used hot decking to impute missing data. The rest of the studies included (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003; Kennedy, et al., 2007) that reported carrying out an intention to treat analysis failed to present that in the results.

2.15 Results

The results of this analysis are derived from six randomised controlled trials of lay-led self-management in adults with arthritis using Cochrane RevMan software.

2.15.1 Primary outcomes of the analysis

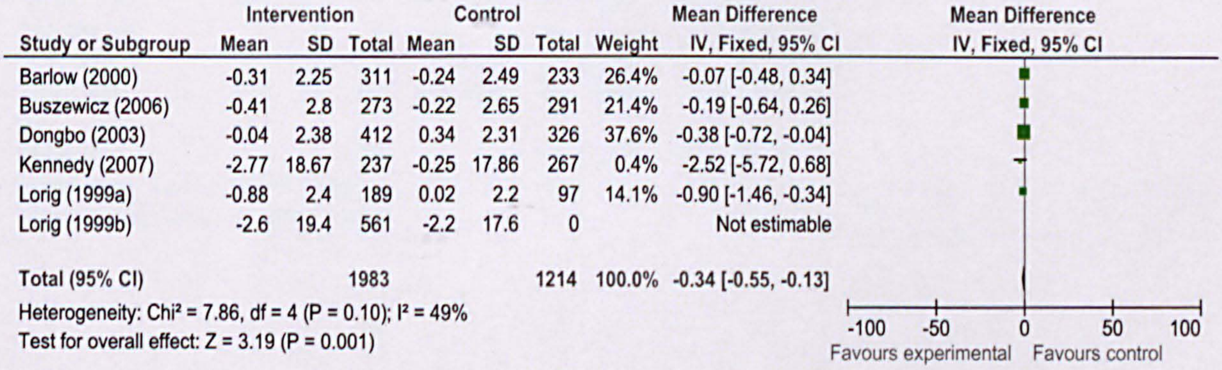
All studies in this analysis reported up to six-month follow up with an exception of two that were made on a one-year follow up. A test for heterogeneity was conducted if appropriate.

2.15.1.1 Health Status

1. **Pain**

All the studies with a combined total of 3197 participants reported outcomes on pain with small heterogeneity (P = 0.10, $I^2 = 49\%$) between the studies. The results showed a statistically significant reduction in pain in favour of the intervention group at 6 months follow up (SMD -0.34 (95% CI -0.55 to -0.13; Z = 3.19; P = 0.001) as illustrated in table (2.12).

Table (2.12): comparing pain up to six month follow up with baseline

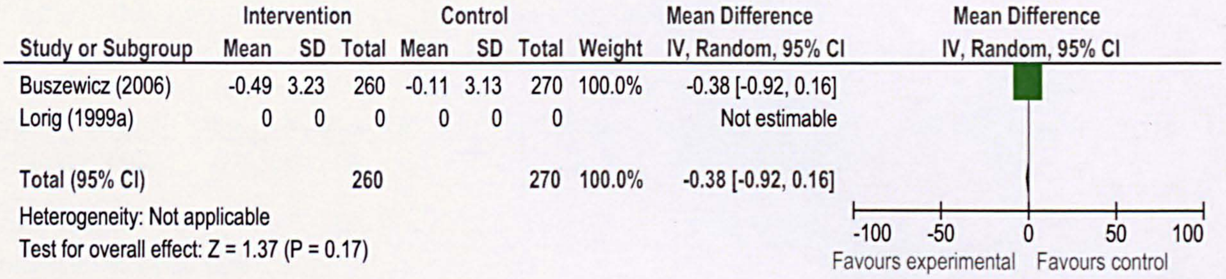


Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Mean Difference IV, Fixed, 95% CI
Barlow (2000)	-0.31	2.25	311	-0.24	2.49	233	26.4%	-0.07 [-0.48, 0.34]
Buszewicz (2006)	-0.41	2.8	273	-0.22	2.65	291	21.4%	-0.19 [-0.64, 0.26]
Dongbo (2003)	-0.04	2.38	412	0.34	2.31	326	37.6%	-0.38 [-0.72, -0.04]
Kennedy (2007)	-2.77	18.67	237	-0.25	17.86	267	0.4%	-2.52 [-5.72, 0.68]
Lorig (1999a)	-0.88	2.4	189	0.02	2.2	97	14.1%	-0.90 [-1.46, -0.34]
Lorig (1999b)	-2.6	19.4	561	-2.2	17.6	0		Not estimable
Total (95% CI)			1983			1214	100.0%	-0.34 [-0.55, -0.13]

Heterogeneity: Chi² = 7.86, df = 4 (P = 0.10); I² = 49%
Test for overall effect: Z = 3.19 (P = 0.001)

Two studies (Lorig, et al., 1999a, Buszewicz, et al., 2006) assessed pain on 12 months follow up with 260 participants reporting. Lorig, et al. (1999a) failed to provide enough results that estimation can be made. Buszewicz, et al. (2006) results failed to show any significant difference between the intervention and control group (SMD -0.38 (95% CI -0.92 to 0.16; Z = 1.37; P = 0.17) as illustrated in the following table (2.13).

Table (2.13): comparing pain up to 12 month follow up with baseline



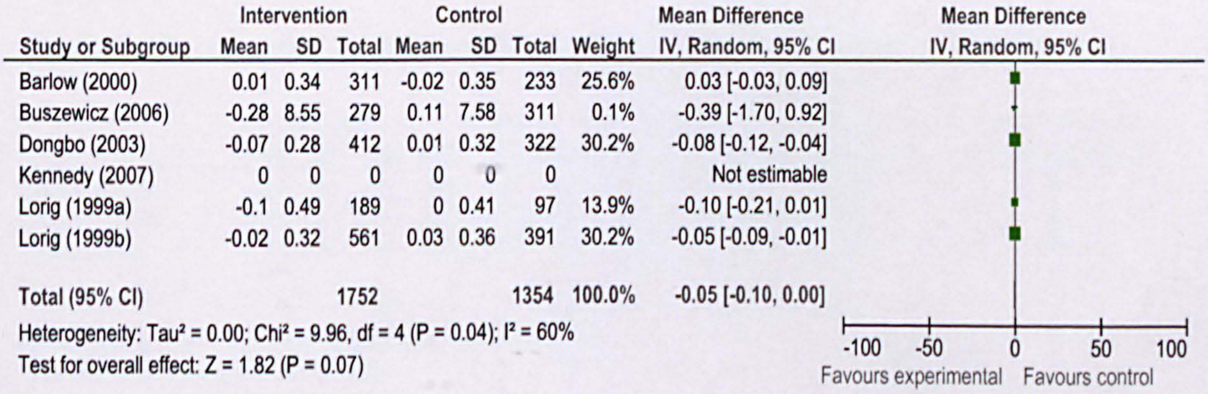
	Intervention			Control				Mean Difference	Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI	IV, Random, 95% CI
Buszewicz (2006)	-0.49	3.23	260	-0.11	3.13	270	100.0%	-0.38 [-0.92, 0.16]	
Lorig (1999a)	0	0	0	0	0	0		Not estimable	
Total (95% CI)			260			270	100.0%	-0.38 [-0.92, 0.16]	

Heterogeneity: Not applicable
Test for overall effect: Z = 1.37 (P = 0.17)

2. Disability

Five studies assessed changes in disability with 3106 participants using different instrument and scales with a reported substantial heterogeneity (P = 0.04; I^2 = 60%) between studies. The results showed a very small statistically significant reduction in disability as a result of the intervention (SMD -0.05 (95% CI -0.10 to 0.00; Z = 1.82; P = 0.07).

Table (2.14): comparing disability up to six month follow up with baseline

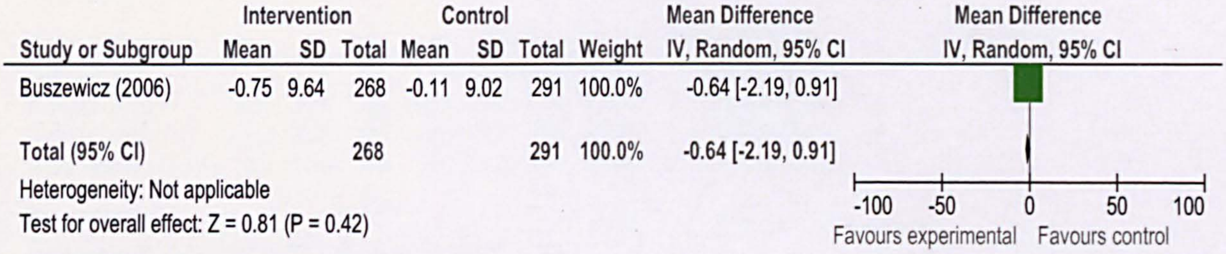


	Intervention			Control				Mean Difference	Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI	IV, Random, 95% CI
Barlow (2000)	0.01	0.34	311	-0.02	0.35	233	25.6%	0.03 [-0.03, 0.09]	
Buszewicz (2006)	-0.28	8.55	279	0.11	7.58	311	0.1%	-0.39 [-1.70, 0.92]	
Dongbo (2003)	-0.07	0.28	412	0.01	0.32	322	30.2%	-0.08 [-0.12, -0.04]	
Kennedy (2007)	0	0	0	0	0	0		Not estimable	
Lorig (1999a)	-0.1	0.49	189	0	0.41	97	13.9%	-0.10 [-0.21, 0.01]	
Lorig (1999b)	-0.02	0.32	561	0.03	0.36	391	30.2%	-0.05 [-0.09, -0.01]	
Total (95% CI)			1752			1354	100.0%	-0.05 [-0.10, 0.00]	

Heterogeneity: Tau² = 0.00; Chi² = 9.96, df = 4 (P = 0.04); I² = 60%
Test for overall effect: Z = 1.82 (P = 0.07)

Buszewicz, et al. (2006) reported changes on 12 months follow up but showed no significant difference between the intervention and the control group in terms of disability reduction (SMD -0.64 (95% CI -2.19 to .091; Z = 0.81; P = 0.42) as described in the following table.

Table (2.15): comparing disability up to 12 month follow up with baseline



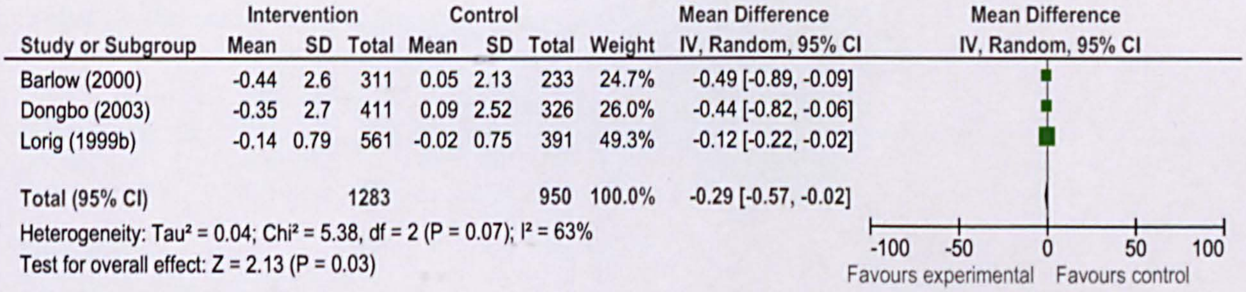
	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Buszewicz (2006)	-0.75	9.64	268	-0.11	9.02	291	100.0%	-0.64 [-2.19, 0.91]
Total (95% CI)			268			291	100.0%	-0.64 [-2.19, 0.91]

Heterogeneity: Not applicable
Test for overall effect: Z = 0.81 (P = 0.42)

3. Fatigue

Three studies (Lorig, et al., 1999b; Barlow, et al., 2000; Dongbo, et al., 2003) out of the six studies included provided data on self reported fatigue at 6 months follow up with substantial statistical heterogeneity (P = 0.07; I^2 = 63%) between them. Results from these three studies showed a small statistically significant reduction in fatigue amongst the intervention group (SMD -0.29 (95% CI -0.57 to -0.02; Z = 2.13; P = 0.03) as illustrated in the following table.

Table (2.16): comparing fatigue up to six month follow up with baseline



	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Barlow (2000)	-0.44	2.6	311	0.05	2.13	233	24.7%	-0.49 [-0.89, -0.09]
Dongbo (2003)	-0.35	2.7	411	0.09	2.52	326	26.0%	-0.44 [-0.82, -0.06]
Lorig (1999b)	-0.14	0.79	561	-0.02	0.75	391	49.3%	-0.12 [-0.22, -0.02]
Total (95% CI)			1283			950	100.0%	-0.29 [-0.57, -0.02]

Heterogeneity: $Tau^2 = 0.04$; $Chi^2 = 5.38$, df = 2 (P = 0.07); $I^2 = 63\%$
Test for overall effect: Z = 2.13 (P = 0.03)

4. Depression

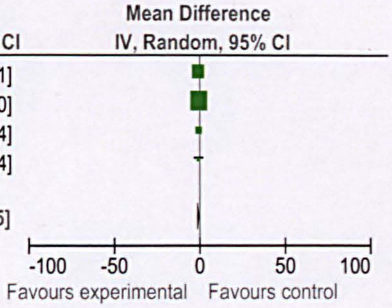
Four studies (Lorig, et al., 1999a; Barlow, et al., 2000; Dongbo, et al., 2003; Buszewicz, et al., 2006) reported data on changes in depression with no heterogeneity between the studies (P = 0.60; I^2 = 0%). The results of this meta-analysis showed a strong statistical significance effect on depression in favour of the intervention group (SMD -0.61 (95% CI -0.87 to -0.35; Z = 4.52; P < 0.00001) as described in the table below.

Table (2.17): comparing depression up to six month follow up with baseline

Study or Subgroup	Intervention Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Barlow (2000)	-1	2.94	311	-0.14	2.42	233	34.3%	-0.86 [-1.31, -0.41]
Buszewicz (2006)	-0.13	2.28	288	0.33	2.24	308	52.9%	-0.46 [-0.82, -0.10]
Dongbo (2003)	-1.2	5.23	385	-0.66	5.17	308	11.5%	-0.54 [-1.32, 0.24]
Lorig (1999a)	-3.2	10.1	189	-2.5	9.3	97	1.3%	-0.70 [-3.04, 1.64]
Total (95% CI)			1173			946	100.0%	-0.61 [-0.87, -0.35]

Heterogeneity: $Tau^2 = 0.00$; $Chi^2 = 1.87$, df = 3 (P = 0.60); $I^2 = 0\%$

Test for overall effect: Z = 4.52 (P < 0.00001)



5. Anxiety and Psychological well-being

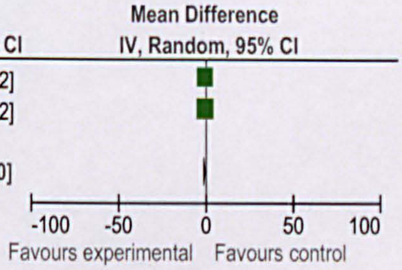
Data were available on changes on anxiety from two studies (Barlow, et al., 2000; Buszewicz, et al., 2006) with no heterogeneity between them (P = 0.72; I^2 = 0%). Results of these studies showed improved anxiety levels which were statistically significant (SMD -0.53 (95% CI -0.85 to -0.20; Z = 3.19; P = 0.001) as in the following table.

Table (2.18): comparing anxiety up to six month follow up with baseline

Study or Subgroup	Intervention Mean	SD	Total	Control Mean	SD	Total	Weight	Mean Difference IV, Random, 95% CI
Barlow (2000)	-0.94	2.87	311	-0.35	2.66	233	48.1%	-0.59 [-1.06, -0.12]
Buszewicz (2006)	-0.15	2.76	286	0.32	2.83	307	51.9%	-0.47 [-0.92, -0.02]
Total (95% CI)			597			540	100.0%	-0.53 [-0.85, -0.20]

Heterogeneity: $Tau^2 = 0.00$; $Chi^2 = 0.13$, df = 1 (P = 0.72); $I^2 = 0\%$

Test for overall effect: Z = 3.19 (P = 0.001)



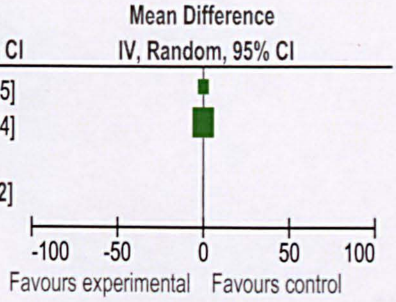
6. Health-related quality of life

Data on changes in health-related quality of life measures using the EuroQol (Brooks, 1996) were available for two studies (Barlow, et al., 2000; Buszewicz, et al., 2006) with a test for heterogeneity (P = 0.25; I^2 = 26%). Although Barlow, et al. (2000) was unclear in the selection of intervention participants, results showed statistically significant improvement in the quality of life at 6 month follow up (SMD -0.07 (95% CI -0.11 to -0.02; Z = 2.91; P = 0.004) as illustrated in the table below

Table (2.19): comparing QoL up to six month follow up with baseline

	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Barlow (2000)	-0.04	0.25	86	-0.01	0.24	78	28.6%	-0.03 [-0.11, 0.05]
Kennedy (2007)	-0.14	0.35	313	-0.06	0.032	316	71.4%	-0.08 [-0.12, -0.04]
Total (95% CI)			399			394	100.0%	-0.07 [-0.11, -0.02]

Heterogeneity: Tau² = 0.00; Chi² = 1.34, df = 1 (P = 0.25); I² = 26%
Test for overall effect: Z = 2.91 (P = 0.004)



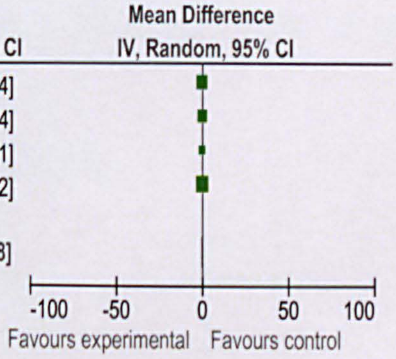
7. Self-rated general health

Four studies (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003; Kennedy, et al., 2007) reported changes in self-rated general health with little heterogeneity (P = 0.15; I^2 = 43%). Meta-analysis of these studies showed strong significant inverse associations favouring the intervention group on 6 months follow up (SMD -0.16 (95% CI -0.24 to -0.08; Z = 3.83; P = 0.0001) as in the table below.

Table (2.20): comparing general health up to six month follow up with baseline

	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Dongbo (2003)	-0.28	0.79	430	-0.03	0.72	349	29.4%	-0.25 [-0.36, -0.14]
Kennedy (2007)	-0.05	0.77	247	0.04	0.7	273	24.2%	-0.09 [-0.22, 0.04]
Lorig (1999a)	-0.33	0.86	189	-0.12	0.82	97	12.5%	-0.21 [-0.41, -0.01]
Lorig (1999b)	-0.09	0.72	561	0.02	0.69	391	34.0%	-0.11 [-0.20, -0.02]
Total (95% CI)			1427			1110	100.0%	-0.16 [-0.24, -0.08]

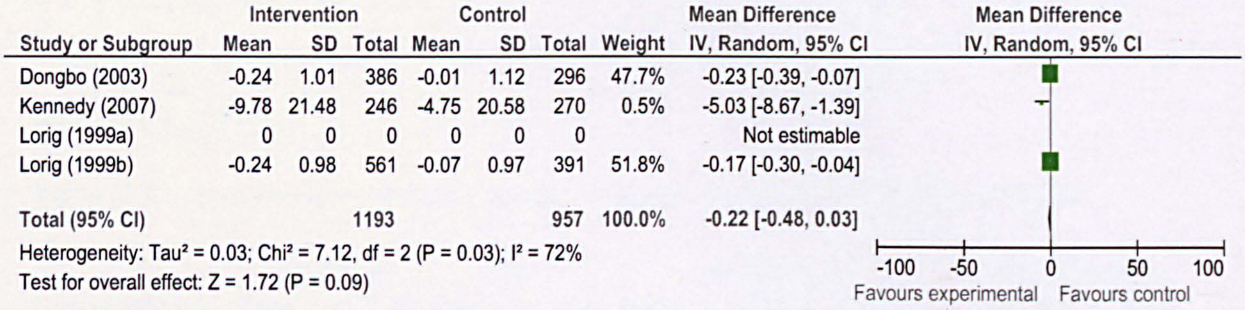
Heterogeneity: Tau² = 0.00; Chi² = 5.30, df = 3 (P = 0.15); I² = 43%
Test for overall effect: Z = 3.83 (P = 0.0001)



8. Health distress

The same four studies that reported on health distress were statistically heterogeneous (P = 0.03; I^2 = 72%). However, results showed no improvement in the intervention group (SMD -0.22 (95% CI -0.48 to 0.03; Z = 1.72; P = 0.09) as in the following table.

Table (2.21): comparing health distress up to six month follow up with baseline



	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Dongbo (2003)	-0.24	1.01	386	-0.01	1.12	296	47.7%	-0.23 [-0.39, -0.07]
Kennedy (2007)	-9.78	21.48	246	-4.75	20.58	270	0.5%	-5.03 [-8.67, -1.39]
Lorig (1999a)	0	0	0	0	0	0		Not estimable
Lorig (1999b)	-0.24	0.98	561	-0.07	0.97	391	51.8%	-0.17 [-0.30, -0.04]
Total (95% CI)			1193			957	100.0%	-0.22 [-0.48, 0.03]

Heterogeneity: Tau^2 = 0.03; Chi^2 = 7.12, df = 2 (P = 0.03); I^2 = 72%
Test for overall effect: Z = 1.72 (P = 0.09)

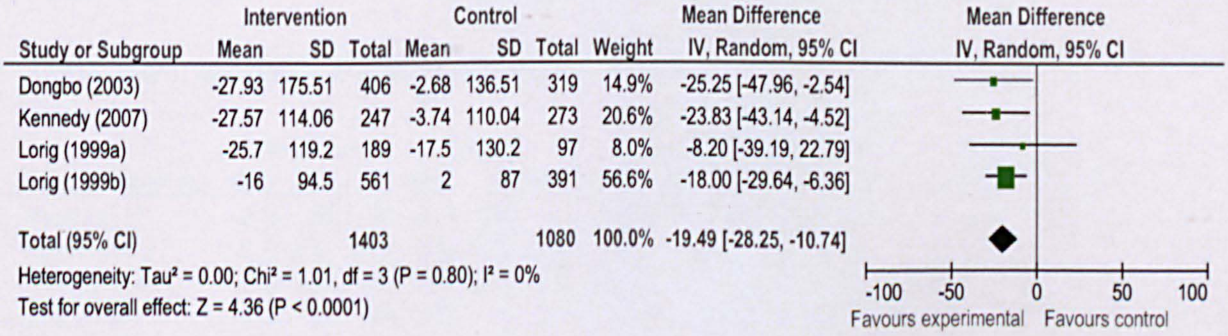
2.15.1.2 Health behaviour

The majority of studies reported health behaviours as outcome demonstrating the following:

1. Exercise

Four studies (Lorig, et al., 1999a; Lorig, et al., 1999b; Dongbo, et al., 2003; Kennedy, et al., 2007) reported changes in the frequency of aerobic exercise with no heterogeneity (P = 0.80; I^2 = 0%). However, results showed strong significance inversely associated in favour of the intervention group (SMD -19.49 (95% CI -28.25 to -10.74; Z = 4.36; P < 0.0001) as illustrated below.

Table (2.22): comparing exercise up to six month follow up with baseline



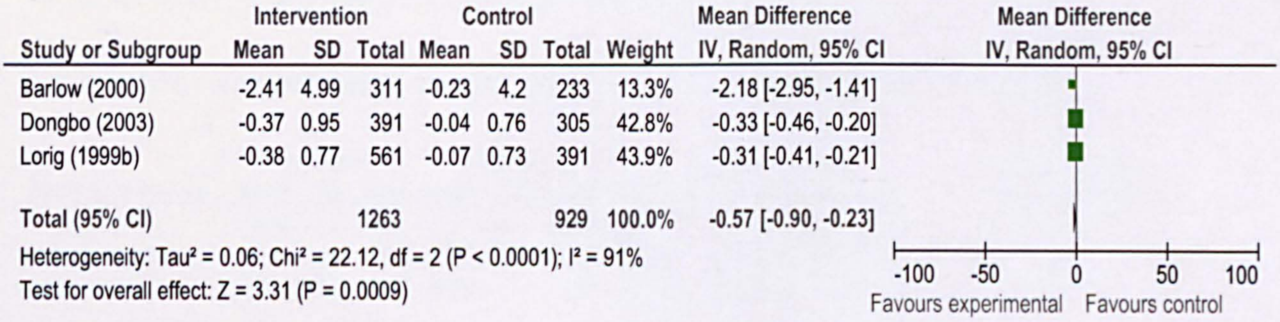
	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Dongbo (2003)	-27.93	175.51	406	-2.68	136.51	319	14.9%	-25.25 [-47.96, -2.54]
Kennedy (2007)	-27.57	114.06	247	-3.74	110.04	273	20.6%	-23.83 [-43.14, -4.52]
Lorig (1999a)	-25.7	119.2	189	-17.5	130.2	97	8.0%	-8.20 [-39.19, 22.79]
Lorig (1999b)	-16	94.5	561	2	87	391	56.6%	-18.00 [-29.64, -6.36]
Total (95% CI)			1403			1080	100.0%	-19.49 [-28.25, -10.74]

Heterogeneity: Tau^2 = 0.00; Chi^2 = 1.01, df = 3 (P = 0.80); I^2 = 0%
Test for overall effect: Z = 4.36 (P < 0.0001)

2. Symptoms management

Changes in cognitive symptoms management was obtained from three studies (Lorig, et al., 1999b; Barlow, et al., 2000; Dongbo, et al., 2003) and have substantial heterogeneity between them (P < 0.0001; I^2 = 91%). Results of these studies showed a statistically significant increase in using various strategies and techniques in the intervention group (SMD -0.57 (95% CI -0.90 to -0.23; Z = 3.31; P = 0.0009) as described below.

Table (2.23): comparing symptoms management up to six month follow up with baseline



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Mean Difference IV, Random, 95% CI
Barlow (2000)	-2.41	4.99	311	-0.23	4.2	233	13.3%	-2.18 [-2.95, -1.41]
Dongbo (2003)	-0.37	0.95	391	-0.04	0.76	305	42.8%	-0.33 [-0.46, -0.20]
Lorig (1999b)	-0.38	0.77	561	-0.07	0.73	391	43.9%	-0.31 [-0.41, -0.21]
Total (95% CI)			1263			929	100.0%	-0.57 [-0.90, -0.23]

Heterogeneity: Tau² = 0.06; Chi² = 22.12, df = 2 (P < 0.0001); I² = 91%

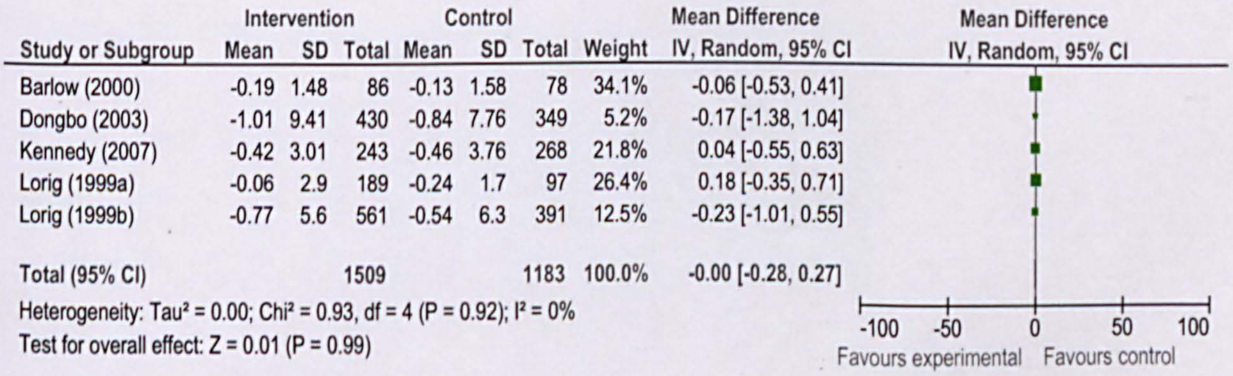
Test for overall effect: Z = 3.31 (P = 0.0009)

2.15.1.3 Healthcare use

1. **General Practitioner and Accident and Emergency department visits**

Five studies (Lorig, et al., 1999a; Lorig, et al., 1999b; Barlow, et al., 2000; Dongbo, et al., 2003; Kennedy, et al., 2007) examined changes in general practitioners visit with no heterogeneity between them (P= 0.92; I^2 = 0%). These studies showed no changes between the intervention or control group in terms of attendance (SMD -0.00 (95% CI -0.28 to 0.27; Z = 0.01; P = 0.99) as illustrated in the following table.

Table (2.24): comparing GP and A&E visits up to six month follow up with baseline



Study or Subgroup	Intervention Mean	Intervention SD	Intervention Total	Control Mean	Control SD	Control Total	Weight	Mean Difference IV, Random, 95% CI
Barlow (2000)	-0.19	1.48	86	-0.13	1.58	78	34.1%	-0.06 [-0.53, 0.41]
Dongbo (2003)	-1.01	9.41	430	-0.84	7.76	349	5.2%	-0.17 [-1.38, 1.04]
Kennedy (2007)	-0.42	3.01	243	-0.46	3.76	268	21.8%	0.04 [-0.55, 0.63]
Lorig (1999a)	-0.06	2.9	189	-0.24	1.7	97	26.4%	0.18 [-0.35, 0.71]
Lorig (1999b)	-0.77	5.6	561	-0.54	6.3	391	12.5%	-0.23 [-1.01, 0.55]
Total (95% CI)			1509			1183	100.0%	-0.00 [-0.28, 0.27]

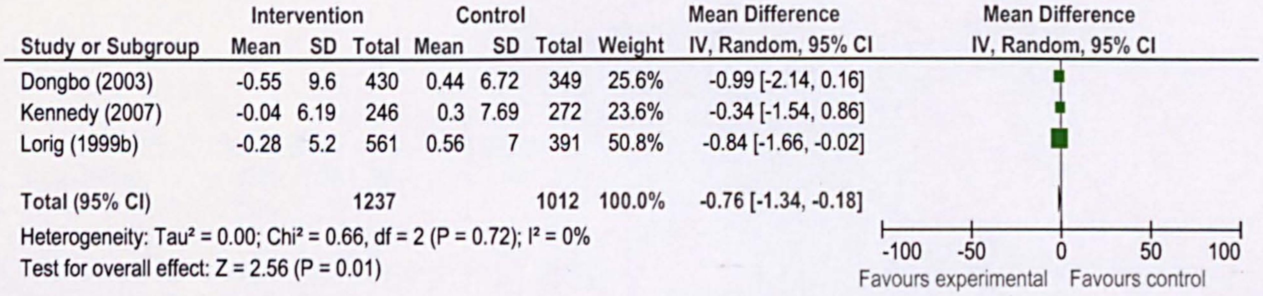
Heterogeneity: Tau² = 0.00; Chi² = 0.93, df = 4 (P = 0.92); I² = 0%

Test for overall effect: Z = 0.01 (P = 0.99)

2. Nights spent in hospital

Changes in the number of days or nights spent in hospital were obtained from only three studies (Lorig, et al., 1999b; Dongbo, et al., 2003; Kennedy, et al., 2007) with no statistical heterogeneity between studies (P = 0.72; I^2 = 0%). Results showed no statistical difference between the intervention and control group (SMD -0.76 (95% CI -1.34 to -0.81; Z = 2.56; P = 0.01) as described below.

Table (2.25): comparing nights spent in hospital up to six month follow up with baseline



	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Dongbo (2003)	-0.55	9.6	430	0.44	6.72	349	25.6%	-0.99 [-2.14, 0.16]
Kennedy (2007)	-0.04	6.19	246	0.3	7.69	272	23.6%	-0.34 [-1.54, 0.86]
Lorig (1999b)	-0.28	5.2	561	0.56	7	391	50.8%	-0.84 [-1.66, -0.02]
Total (95% CI)			1237			1012	100.0%	-0.76 [-1.34, -0.18]

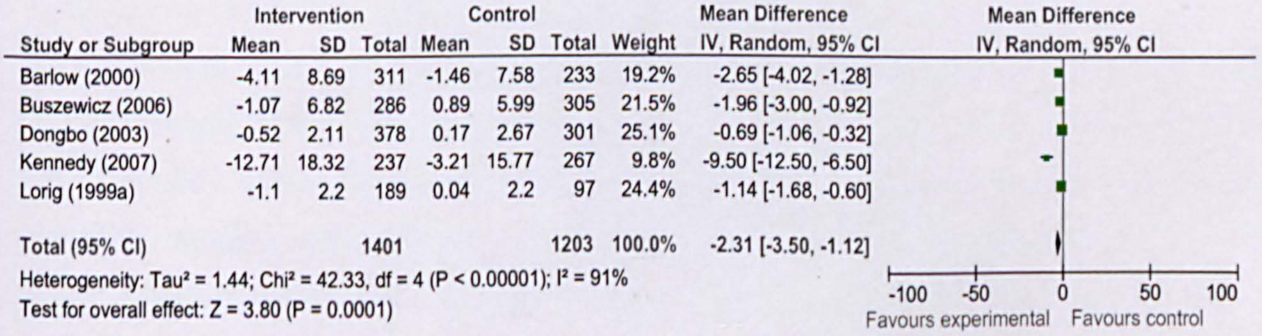
Heterogeneity: Tau² = 0.00; Chi² = 0.66, df = 2 (P = 0.72); I² = 0%

Test for overall effect: Z = 2.56 (P = 0.01)

2.15.1.4 Self-efficacy to manage symptoms

Most of the studies included (Lorig, et al., 1999a; Barlow, et al., 2000; Dongbo, et al., 2003; Buszewicz, et al., 2006; Kennedy, et al., 2007) reported an improvement in participants' self-efficacy with substantial heterogeneity between studies (P < 0.00001; I^2 = 91%). Meta-analysis showed significant improvements in self-efficacy amongst participants who received the intervention (SMD -2.31 (95% CI -3.50 to -1.12; Z = 3.80; P = 0.0001) as illustrated in this table.

Table (2.26): comparing self-efficacy up to six month follow up with baseline



	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Barlow (2000)	-4.11	8.69	311	-1.46	7.58	233	19.2%	-2.65 [-4.02, -1.28]
Buszewicz (2006)	-1.07	6.82	286	0.89	5.99	305	21.5%	-1.96 [-3.00, -0.92]
Dongbo (2003)	-0.52	2.11	378	0.17	2.67	301	25.1%	-0.69 [-1.06, -0.32]
Kennedy (2007)	-12.71	18.32	237	-3.21	15.77	267	9.8%	-9.50 [-12.50, -6.50]
Lorig (1999a)	-1.1	2.2	189	0.04	2.2	97	24.4%	-1.14 [-1.68, -0.60]
Total (95% CI)			1401			1203	100.0%	-2.31 [-3.50, -1.12]

Heterogeneity: Tau² = 1.44; Chi² = 42.33, df = 4 (P < 0.00001); I² = 91%

Test for overall effect: Z = 3.80 (P = 0.0001)

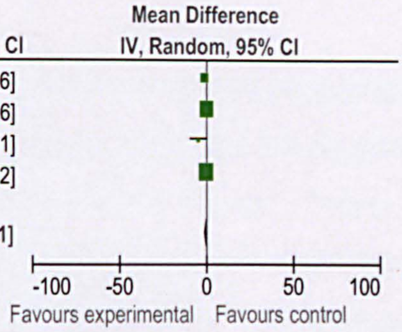
2.15.1.5 Communication with health professionals

Four studies (Lorig, et al., 1999b; Barlow, et al., 2000; Dongbo, et al., 2003; Kennedy, et al., 20007) reported changes in communication with health professionals. Results reported a small statistical significant improvement in favour of the intervention group but with substantial heterogeneity between the studies (P = 0.001; I^2 = 81%) as described in this table.

Table (2.27): comparing communication with professionals up to six month follow up with baseline

	Intervention			Control				Mean Difference
Study or Subgroup	Mean	SD	Total	Mean	SD	Total	Weight	IV, Random, 95% CI
Barlow (2000)	-1.42	4.38	311	-0.22	4.32	233	16.5%	-1.20 [-1.94, -0.46]
Dongbo (2003)	-0.04	1.24	396	-0.11	1.32	308	40.2%	0.07 [-0.12, 0.26]
Kennedy (2007)	-2.78	26.07	236	1.9	26.08	267	0.7%	-4.68 [-9.25, -0.11]
Lorig (1999b)	-0.26	0.98	561	-0.11	0.96	391	42.7%	-0.15 [-0.28, -0.02]
Total (95% CI)			1504			1199	100.0%	-0.26 [-0.64, 0.11]

Heterogeneity: $Tau^2 = 0.08$; $Chi^2 = 16.02$, df = 3 (P = 0.001); $I^2 = 81\%$
Test for overall effect: Z = 1.38 (P = 0.17)



2.16 Discussion

This meta-analysis systematically analysed and evaluated 6 RCTs examining the effectiveness of self-management education programmes for patients with a chronic arthritis condition. Because there is no accepted universal definition of what constitutes a chronic self-management programme, all the studies shared a similar structure and components of an internationally reputed CDSMP that was designed by Kate Lorig and her team at the Stanford University of California. However, important cultural adaptations of the concepts, content and processes were made to the original programme in order to suit the communities receiving the intervention. For example, Dongbo, et al. (2003) adapted this programme to suit the Chinese culture. Lorig, et al. (1999a) made similar changes to adapt to Spanish speaking communities in the USA and Kennedy, et al. (2007) made the required cultural changes to anglicise the original CDSMP version. Nonetheless, a substantially statistically-significant heterogeneity was displayed between the studies in terms of reported outcomes and their effect.

Only one study (Buszewicz, et al., 2006) reported changes on outcomes beyond six months, whilst the rest of the studies measured short term outcomes up to six months and compared them to baseline data. Therefore, in this meta-analysis there were statistically significant short term outcomes of up to six months, but insufficient information to assess the sustainability of these positive outcomes beyond 6 months. The studies detected positive effects of self-management on reducing pain amongst patients who received the intervention and further evidence suggested they enjoyed improved psychological wellbeing and suffered less depression and anxiety. The currently available data did not show any significant evidence in favour of the intervention group compared to the control group to suggest improvement in disability or fatigue in general.

Synthesis of the included studies suggests evidence associated with improved general self-rated health as well as improved health related quality of life amongst participants who received the intervention in comparison with participants who did not. There is also evidence suggesting that these interventions may be associated with short term reductions in health distress and increased use of cognitive symptoms management techniques. Patients in the intervention groups tended to exercise more frequently in comparison with the control groups according to the detected evidence.

There is strong evidence from this meta-analysis that attending self-management programmes significantly improves empowerment and psychological self-efficacy to manage symptoms and conditions at 6 months follow up ($P<0.0001$). The currently available data did not show any significant effects of lay-led self-management interventions on service utilisation as it failed to improve the number of visits made to a general practitioner or emergency department; the number of days or nights spent in hospital.

2.16.1 Health care costs

Although Dongbo, et al. (2003) estimated the cost per patient of attending the programme as 82.7 Chinese Yuan, there was only one study that reported a cost effective analysis. Kennedy, et al. (2007) reported the cost of attending the programme in the UK setting (£250 per participant) but complete information is not yet available.

2.16.2 Generalisability and limitations of the meta-analysis

As with all clinical trials, it is possible that participants in the studies may not be truly representative of the local adult population with arthritis, as people who take part in clinical trials tend to be more committed and motivated. Although having motivated participants will not affect differences between the two groups, it may affect the generalisability of the results if self-management programmes are provided as a routine treatment.

The studies were carried out in various developed countries (USA, UK and China), but there were no studies from developing countries. Although ethnicity was reported in some of the studies, there was not enough information to perform a subgroup analysis for ethnicity. However, there is no evidence to suggest that self-management programmes would not be suitable to be delivered to ethnic minority groups or in developing countries. It is also evident that these programmes if delivered to ethnic minority groups in a language that they are familiar with could still deliver the same benefits.

This meta-analysis' primary objective was to examine the effectiveness of lay-led self-management programmes with primary outcomes examining health status, health behaviours, healthcare use and self-efficacy. Although the analysis showed improved health status and health related quality of life, it failed to show similar results on the longer period of time as the included studies did not report any outcome beyond 6 months except for two studies. Evidence from this review did not appear to reduce GP or healthcare resource use.

Evidence from the data currently available is unable to identify whether disease specific lay-led programmes are more or less effective than generic programmes. It is also not possible to determine which components or aspects of interventions are more effective than others. This review did not examine which is more effective (lay-led or professionally-led) as it only included clinical trials that were lead by lay volunteers.

This meta-analysis has several limitations in addition to those previously mentioned. The varied methodological quality of the originally included studies (High to moderate) is one of the limitations. Although meta-analysis methods allow for adjustments for study-level differences, the reviewer cannot take account of inherited biases from individual studies. A second limitation is the presence of possible publication bias, although this does not invalidate the findings, the findings should be interpreted cautiously.

2.17 Conclusion

The 6 studies included in this meta-analysis provided evidence that arthritis lay-led self-management programmes for adults results in a clinically important impact on health status, improved health behaviours and increased self-efficacy to manage symptoms. No evidence was detected on long term improvement due to the lack of long term follow up and/or information on outcomes. It has been observed that providing additional education sessions on an annual basis or incorporating an education element in the services patients receive could result in long-lasting benefits to health and psychological outcomes.

There is no evidence of an effect on healthcare use and resource utilisation. However, because of heterogeneity in interventions, study populations, follow up times and outcomes measured, data are still insufficient to give clear recommendations regarding the contents of self-management programmes in arthritis.

There is no evidence to suggest which setting is more effective to deliver the self-management programme; neither the person delivering the programme whether it is professional or lay volunteers. However, programmes that used the principles of empowerment, participation and adult learning are proved to be effective.

For self-management interventions to have greater uptake, thought should be given to how and when they are offered to patients. Introduction and endorsement of these programmes at a physician visit will probably ensure higher rates of participation. It should also be recognised that as with medication, one therapy or programme might not be suitable for all patients. Identifying who benefits most from various self-management interventions is an important addition to any assessment, and could lead to more effective targeting of resources.

If self-management interventions are to be more widely adopted in health care, training in skills such as group facilitation, problem solving, goal setting and cognitive behavioural techniques need to be enhanced. They are not usually part of most health-care professionals' training. If these interventions are to be delivered appropriately and effectively, training in the skills needed by health-care professionals who deliver these programmes needs to be recognised and appropriate courses developed.

Clearly, meta-analysis has an important role in medical research, public policy, and clinical practice. Its use and value will likely increase, given the amount of new knowledge, the speed at which it is being created, and the availability of specialized software for performing it. However, the fundamental limitations of Meta-Analysis exist in, that only quantitative empirical research studies (RCTs) are used. Data will be typically found in articles or other publications and normally it is impossible to get the complete data sets. Two important restrictions result from this. The findings must be conceptually comparable and deal with the same constructs and relationships. Secondly the findings must be configured in similar statistical forms. And that is one of the biggest problems.

Alternatively, this research in the following chapters will present a collaborative approach that takes into account patient experience and qualitative data that was not in the merit of this meta-analysis.

Section III: From Compliance to Concordance "the way forward"

2.18 Introduction

As stated previously in chapter one, usage of the term concordance in ophthalmic practice has yet to come to the force. Presently adherence is the term used. Patient adherence with chronic medical treatments is known to be far from ideal (Schwartz and Quigley, 2008). Research has demonstrated that approximately 9% of all prescriptions written across all therapeutic areas are never filled, especially at initial stage of treatment (Lash and Harding, 1995), which is a reflection on non-compliance with medication taking. The scope of this issue is enormous throughout chronic condition literature; diseases that are asymptomatic in nature like COAG are more prone to non-compliance and therefore poor adherence (Dimatteo et al, 2002) with studies suggesting it could be as high as 80% (Olthoff et al, 2005). Concordance as such becomes an impossibility in these conditions.

Ocular hypotensive drugs are prescribed to patients with COAG to prevent the occurrence of glaucoma and minimise the visual field loss by slowing the progression rate of the disease in individuals with high IOPs and so preserving their vision (Nordstrom et al, 2005). It is important that these drops are taken regularly on a daily basis for life (Gray et al, 2009). Failing to do so, could be mistaken for the lack of effectiveness of treatment prescribed which might result in additional risks and costs because of more hospital appointments and diagnostic tests; switching to other medications and/or waste of unfinished pharmaceutical supplies, and ultimately advancing to subsequent surgical intervention (Bissell et al, 2004; Hoevenaars et al, 2008; Gray et al, 2009). In order for concordance to the medical regimen to become a possibility, patients must be willing to collaborate with healthcare professionals in their treatment and subsequently adhere to the medical regimen (Refer to section 2.10 on changing terminology for clarification.).

In the main, literature exploring glaucoma treatment adherence is vast, reflecting the variation in terminology used to describe it, interventions and strategies designed to tackle poor adherence, its 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, but none can be considered as consistently predictive.

2.18.1 Changing Terminology

This section will not seek to review the literature; however, it will explore how terms that denote patient behaviour towards medication use have become more precise and empowering over time. Although the term 'compliance' has been used extensively in the medical model approach to refer to the extent to which patients' behaviours' correspond with providers' recommendations (Schwartz, 2005) and implies their obedience to physician 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 by some (but by no means all) for a more precise and less judgmental term, called adherence (Gray et al, 2009). Adherence in this sense is synonymous with compliance and has association with concordance as will be shown further on in this section. 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 clearly justified blaming patients for not acting in accordance with doctors' instructions and expectations (Amro and Cox, 2011b).

Mead and Bower (2002) highlighted the limitations of 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 health professionals can be pooled together to arrive at mutually agreed goals. In other words, health 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 (Amro and Cox, 2011b).

According to a multidisciplinary group of health 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), where it is increasingly referred to in health services research. In contrast to compliance and adherence, William and Calnan (1996) noted that concordance fits neatly with the political landscape of the NHS in the UK and is congruent with ideas such as shared clinical decision making and 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 (William and Calnan, 1996). Nonetheless, there is a need for more empirical research that can shed light on concordance relevant to patients with chronic conditions like COAG (Bissell et al, 2004). The research that is explicated in this study has not intended to foster concordance in the traditional sense, as it has not examined the doctor-patient relationship. The intervention explicated in this study has been associated with Expert Patient-patient interaction. Despite its eloquence, Justis (2010) has argued that the concordance approach has not been widely adopted. Notwithstanding, this collaborative approach was important in harnessing the experiential knowledge patients gained in this study where they received the Expert Patient intervention, which seeks to empower them and improve their knowledge and skills in self-management of their condition.

Like concordance, 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). 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.

For the purpose of this study, the term adherence is used throughout this Thesis and refers to gaps in the therapy whenever possible whilst persistence will be used to refer to continuous use of medication. As noted previously, the term concordance, preferable over other terms, was not used in the setting where the study was conducted. Healthcare professionals are more familiar with the terms adherence and compliance. To prevent confusion and a delay in approval for the research to proceed, by the Research and Development Committee, the term adherence has been used in questionnaires and application forms where changing the word to concordance proved problematic.

2.18.2 Measuring Adherence and Persistence

Assessing adherence and persistence 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 prescription.

2.18.2.1 Patient Self-Report

Using a numerical scale that allows patients to mark along a scale where patients think their answers should be without being 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 agree 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 the study. In this study, a self-reported scale of 1 to 10 representing the times patients have missed their eye drops in the past four weeks has been used.

2.18.2.2 Monitoring Devices

In theory, an electronic monitoring device of dosing is considered the most reliable tool (Olthoff et al, 2005). However, these devices cannot prove that a drop truly went in to 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 has become smaller and unobtrusive and more manageable to use (Hermann and Diestelhorst, 2006). However these devices are prohibitively expensive. It is viewed that it will be some time before more accurate and cost-effective devices are available for use (Gray et al, 2009).

2.18.2.3 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) argued that this method provides accurate estimation of persistence; however, obtaining a repeat prescription of a particular drug does not necessarily mean that they will be used as prescribed or used at all.

2.18.3 Barriers and Interventions to Improve Adherence

Assessment of adherence barriers relies primarily on patients' attitudes and thoughts that are well located in the merit of qualitative research (Lacey et al, 2009). Despite the recent 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 USA. 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 (2.28). The taxonomy formulated in this study could be useful in assisting health professionals develop individualised interventions that optimise patient education and problem solving regarding their health care. Another qualitative study by Taylor et al (2002) explored poor adherence amongst glaucoma patients and revealed that forgetfulness was the main reason for poor adherence. This was followed by an inability to instil eye drops even though patients thought they could, treatment side effects, complexity of treatment regimens, glaucoma knowledge and education, trying new treatment options and the cost of treatment.

Table (2.28): Categories of barriers to adherence

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

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 (physically unable to instil the drops, needing more assistance, forgetting drops in the elderly as compared to feeling depressed as glaucoma is an elderly disorder amongst younger patients).

Based on the above barriers, numerous studies have set out to improve adherence of glaucoma patients to their treatment by improving one (or more) of the identified barriers. It would be impossible to review all these studies; instead, three main reviews (Olthoff et al, 2005; van Dulmen et al, 2007; and Gray et al, 2009) that examined the evidence from these single studies will be considered in relation to interventions designed to overcome barriers. These interventions are: educational and individualised care planning, drug comparison, and reminder devices.

2.18.3.1 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 that then help patients to identify suitable times for instilling and storing 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. This is in addition to the quality of patient-provider interaction and the way information is passed (van Dulmen et al, 2007).

2.18.3.2 Drug Comparison (Technical Interventions)

Most adherence intervention 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.

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

None of the three reviews found any convincing evidence to advocate any 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 included in his review lacked a thorough behavioural theory basis. A conclusion shared by van Dulmen et al (2007) who added that further studies are needed to explore the theoretical components of these interventions. Gray et al (2009) did not find convincing evidence to recommend any particular intervention for improving adherence amongst glaucoma patients. This research, however, explicates a model that improves glaucoma concordance.

2.19 Summary

COAG is the most common form of glaucoma, with an adult onset in the early forties. Population-based studies have confirmed the markedly elevated risk of COAG among black Africans, although the basis for this excess risk remains unclear. Age and elevated IOP are the most well established risk factors for COAG across all population groups. Family history of glaucoma is also another major risk factor although this association has yet to be understood. Early detection and prompt treatment could save patients losing vision making glaucoma screening high on the public health agenda.

Glaucoma treatments often produce side effects and frequently fail to address the psychosocial needs of people with COAG. A self-management programme may provide the answers to questions usually asked about glaucoma patients' understanding of their condition and adherence to their treatment regimens. An Expert Patient Programme approach has long been adopted by the DoH but not in relation to patients with COAG. Training programmes are being offered on various chronic conditions but again not in relation to COAG. Positive health outcomes and improved communications between patients and health professionals have made self-management programmes popular across the world. This concept will be explored further in the following chapter.

CHAPTER THREE

The Rise of Self-Management and Collaborative Health Care in Chronic Conditions: Policies, Theories and Analysis of the Literature

3.0 Introduction

This chapter explores the concept of self-management in chronic conditions and the policies surrounding self-management and the Expert Patient Programme. It reviews the strategies, models and outcomes of self-management. Theories of health behaviour change are also analysed with an emphasis on self-management and adherence. The chapter concludes by discussing the Information-Motivation-Behavioural skills (IMB) model upon which the Glaucoma Expert Patient Programme (GEPP) of the study is based.

3.1 The Rise of Self-Management: Self-Efficacy.

The last century has witnessed an unprecedented demographic and epidemiological transition that has had a radical impact on health and health service provision in developed countries such as the UK (Taylor and Bury, 2007). The greater prosperity and the success of the pharmaceutical and medical technology after the Second World War have helped to create new public health challenges marked by the emergence of chronic conditions as the central health care issue (Holman and Lorig, 2004). In the 1960s and 1970s, ideas associated with what is now known, as "self-management" was part of the new social movement in health. It challenged the existing medical practices and sought to establish new agendas and terminology around collaborative health care (Schiller and Levin, 1983). With an ever rising prevalence of chronic disease, at this stage, the impact of these diseases on patients' ability to engage in normal activities "physical functioning" was recognised.

The Grounded Theory work of Strauss and his colleagues (Strauss and Corbin, 1998; Glaser and Strauss 1967) in the USA was instrumental in putting the everyday struggle of individuals with chronic conditions on the sociological map. In his work, Strauss emphasised the public health impact of chronic conditions and its implication for the development of health services that meet their needs (Strauss, 1975; Corbin and

Strauss, 1992). These insights were taken on by Bury (1982) in the UK, who conducted a study of rheumatoid arthritis (RA). He developed a framework in which he examined 'disruptions of social relationships and the ability to mobilise material resources' among the chronically ill. It documented the 'before and after' character of life with a chronic illness, and dealt with three main stages of illness experience: Onset, and problems of explanation and legitimation, the impact of treatment and the development of adaptive resources (Bury, 1982).

During the 1980s and 1990s, in a response to this growth of chronic disease morbidity and the consequent demand of health care, countries in the developed world began to align themselves closely with the sentiments of the new social movement in collaborative health care and its activities that were concerned with self-management (Newbould et al, 2006). In this changing political climate, the Stanford Arthritis self-management programme (a USA initiative run by Kate Lorig), found a new role for lay people that empowered and involved them in the care process in a participatory way (Holman and Lorig, 2004). Through the use of participative techniques such as modelling and action planning these programmes have fostered self-care amongst patients with chronic conditions (Taylor and Bury, 2007). This situation has created new roles and responsibilities for both patients and health care professionals where patients are expected to be an active and collaborative partner and assume greater responsibilities in the care process (Newbould et al, 2006).

These programmes are based on Bandura's social cognitive theory of behaviour, which emphasises the importance of self-efficacy in predicting successful behaviour change. It refers to the strength of a person's belief in their capabilities to produce designated levels of performance that influence events that affect their lives (Bandura, 1994). In Chronic Disease Self-Management Programmes (CDSMP), self-efficacy is viewed as a mediating construct for behavioural change (Bandura, 1986).

Self-efficacy is specific to a particular behaviour or situation, and is not usually generalised on other similar types of behaviours (Rogers, 2009). For instance, patients may feel high self-efficacy about instilling their eye drops on time, but feel far less self-efficacy managing the side effects of their drops. In this sense, self-efficacy effects the person's expectations of success and failure, and therefore, influences the person's selection of those behaviours, the effort expended on the behaviours; especially after experiencing failure (Michie and Abraham, 2004). In other words, patients who experience a further loss of visual field and/or deteriorated visual acuity, in spite of adhering to the treatment regimens, will presume the task is difficult and will not adhere to their treatment regimen, perhaps due to low self-efficacy.

3.1.1 Self-Management: Definition and Conceptual Clarity

Recognising what is known about self-management and identifying gaps in its theory and research will enhance a common understanding of this phenomenon (Lorig et al, 2005). To better understand this concept, first the key concepts of self-management will be identified. These include: chronic disease self-management skills are learned and health behaviours are self-directed; motivation and self-confidence (or self-efficacy) are important determinants of an individuals' performance of self-management; the social environment and health care system can support or impede self-management; and monitoring and responding to changes in the illness, symptoms, emotions and functioning improves adaptation (Wagner, 1998). Building on these concepts, and bearing in mind the complexity and multidimensional nature of this phenomenon, Von Korff et al (1997) provided a four dimensional definition of self-management as the following:

- Engaging in activities that promote health, build psychological reserve and prevent adverse sequela;
- Interacting with health care providers and adhering to agreed treatment plans;
- Monitoring physical and emotional status and making appropriate management decisions on the basis of the results of self-monitoring; and
- Managing the effects of illness on the patient's ability to function in important roles, emotions, self-esteem, and relationships with others.

However, when analysing the literature of self-management, there was a considerable variation in the understanding of this concept across authors and programmes of research. Historically, self-management has been used in the chronic disease health care context to refer to three different phenomena; a process, a programme, or an outcome (Ryan and Sawin, 2009). The *process* of self-management refers to the use of self-regulation skills to manage chronic conditions or risk factors (Bodenheimer et al, 2002). This process requires learning self-management skills such as goal setting; self-monitoring; reflective thinking; decision making; planning for and engaging in specific behaviours; self-evaluation; and management of physical, emotional and cognitive responses associated with health behaviour change (Lorig and Holman, 2003). The *programme* or *intervention* associated with self-management is designed by health care professionals for the purpose of preparing individuals with chronic conditions to assume the responsibility for managing their conditions and engaging in health promotion activities (Lorig et al, 2001; Wagner, 2007). Self-management has also been used to describe *outcomes* achieved by engaging in the self-management process. Such outcomes include decreased pain, improving levels of activity, or improving adherence to therapeutic regimens (Adams et al, 2007; Chodosh et al, 2005).

Self-management is closely related, but distinct from concepts like self-care and patient education (Riegel et al, 2007). A common theme in defining self-care and self-management is that it is a hallmark of the management of all chronic illnesses (DoH, 2002), and requires the acquisition of new knowledge and skills (Watt, 2000). Self-care has been used to refer to performance of activities of daily living and engaging in health behaviours without the direct collaboration from a legitimate healthcare source (Clark et al, 1991).

Patient education, however, is often used interchangeably with self-management programmes or intervention (Ryan and Sawin, 2009). Patient education is a method of providing information which has been associated with outcomes such as increased knowledge, improving satisfaction, or to change individual preparedness to engage in healthy behaviours whereas self-management activities are designed to enhance changes in health behaviour (Lorig, 2003).

3.1.2 Strategies to Promote Self-Management

Intervention programmes that were designed to promote self-management in chronic conditions in the literature have followed one or more of the following strategies: Information giving and self-management intervention programmes.

3.1.2.1 Information Giving

Historically, there is a general assumption that improving patient knowledge and giving information will lead to increased self-management skills. Heisler et al (2002) pointed out that for knowledge to develop; information should be presented in a clear manner and appropriately placed. The timing and form of the information is equally important with patients appearing to be most receptive of information at first hospital admission or when newly diagnosed (Sylvain and Talbot, 2002). Written materials in the form of leaflets, handouts, or even electronic forms of CDs or websites could potentially reinforce oral information (Kennedy, 1999). However compelling and necessary, information alone is insufficient to bring about changes in self-management behaviours (Gifford and Groessl, 2002). A similar view shared by Hoevenaars et al (2008) has concluded improving glaucoma knowledge would not necessarily improve patients' adherence levels.

3.1.2.2 Self-Management Intervention Programmes

Self-management education programmes aim to empower patients through providing information and teaching skills and techniques to improve self-care and interactions with health care services, with an ultimate goal of improving quality of life (Jordan and Osborne, 2007). These programmes can take generic or condition specific form and can be lay or professionally-led. Content may range from general guidance and support to a prescriptive content covering information, drugs, symptoms, psychological distress, social support, life style and/or communication (Sylvain and Talbot, 2002). Many programmes utilise a cognitive behavioural approach in an attempt to initiate new healthy behaviours and encourage behavioural change (Van Korff et al, 2002). All of these types of programmes will be addressed in later sections of this chapter.

3.1.3 Self-Management Programme Models

The Stanford CDSM model, based on Bandura's theory of self-efficacy, has been the best researched and used approach to self-management (Lorig, 1996). Researcher Kate Lorig and colleagues at Stanford University found that participants reported that change in health status was associated with feelings of personal control rather than changes in behaviour (Lorig and Holman, 2003). Later studies confirmed that enhanced self-efficacy contributed to improvements in health status experienced by participants of self-management programmes. The key features of self-management programmes were teaching strategies that enhance self-efficacy. A set of core skills and knowledge that form the foundation of self-management programmes can be adapted to meet the individualised needs of participants appropriately. These core skills include 'problem-solving, decision-making, resource utilisation, forming of a patient/health care provider partnerships and taking action' (Lorig and Holman, 2003:2). Therefore these core skills can be applied across a range of conditions (Holman and Lorig, 2004).

The Stanford CDSM is a community group-based, six-week course, facilitated by lay leaders or health professionals (Lorig, 1996). Health professionals train course leaders to deliver the Stanford CDSM courses under license to the Stanford Education Centre in California. The Stanford programme was originally developed for arthritis, and has since been modified for people with a range of chronic conditions. The arthritis self-management programme and generic CDSM programme course are conducted in a range of languages including French, Spanish, Japanese, Arabic, German, Chinese and many others. It has been adopted widely in almost all the developed countries with an increasing interest from developing countries (Amro et al, 2010).

The Flinders Model is a course that teaches health care providers the skills to promote patient self-management, based on a collaborative, motivational counselling framework (Flinders Human Behaviour and Health Research Unit, 2004). The course is licensed to Flinders University in Adelaide and provides a structured interview format and written tools for the health care providers to use with individual patients to assess self-management behaviours and personal barriers to self-care and to guide patient-centred problem definition and goal setting. The model has been adopted widely in primary care and community health services (Wilson and Mayor, 2006).

In addition to the Stanford CDSM programme and Flinders Model, disease-specific health education programmes are conducted in hospitals and community health services such as the arthritis, asthma, diabetes and cardiac rehabilitation programmes that are well established in the UK (DoH, 2002).

3.1.4 Self-Management Outcomes

Kate Lorig's model of the CDSM in its generic form has followed particular criteria to best capture the impact of the interventions delivered. This criterion has been widely used in other studies (Lorig, 1996). In a Cochrane review, Foster et al (2009) reviewed 16 RCTs that examined common chronic conditions and summarised all the outcomes that were measured in these studies at baseline and monitored over 6 months and 12 months by some of them.

Primary outcomes are:

- Health status: including patient self-rating quality of life, disability, pain, fatigue, psychological well-being;
- Health behaviour: including exercise, cognitive symptoms management, and adherence;
- Clinical improvement: in examination findings as judged by observers;
- Healthcare use: including doctors' visits, outpatient doctor visits, emergency room visits, hospital admissions and length of stay;
- Self-care and self-efficacy: represents a person's confidence to carry out self-management behaviour.

Secondary outcomes are:

- Knowledge of the condition;
- Change in clinical exam findings;
- Quality of life measures;
- Communication with professionals;
- Cost of delivering programmes.

3.2 Policy Formation Related to Chronic Illnesses and Self-Management

Policies concerned with the health care of chronic conditions, relate to normative lifestyles and desirable behaviours, which to an extent have been based on a "blame culture", where individuals are blamed or held responsible for their illness (Rogers, 2009). Whilst previous policies have focused on what patients should do to maintain their health, the new self-management policy approach is focused on what sort of person the patient should become (May, 2006).

In the UK, whilst the Department of Health (DoH, 2004) acknowledged the impact chronic conditions have on the quality of life of patients and their families, this is often subsumed by the focus on resource issues within policy papers (Wilson and Mayor, 2006). Considerable resources have been allocated to support and run such programmes. A major attraction for health care planners and policy makers has been the expectation that such courses will reduce the use of health care and will deliver long term cost savings (Wanless, 2002). Whilst the effectiveness of the self-management programmes will be discussed in-depth later on in this chapter, it is appropriate to note at this stage that the challenge for policies is not only to ease the demand on resources, but also to improve the principles of patient participation, collaboration and choice.

There are two main arguments that have driven the shift in policies toward increasing self-management and patient involvement in health care services (Coulter, 1999). First, it is a democratic and ethical right for the patients to be involved in decisions about their care and its organisation. Secondly, the evidence has supported the argument that greater patient involvement in the consultation and health care generally will improve their satisfaction with health care and more importantly may lead to better health outcomes (Griffiths et al, 2007).

3.2.1 An Overview of the Policies

Following its election in 1997, the UK Labour Government planned a 10 year programme of major reformation and modernisation of the National Health Service (NHS). With the appearance of self-management programmes as a strategy to manage the high demand of health care in the USA in the early 1990s, new policy proposals were ready to be put forward. In December 1997, the DoH (1997) published the White Paper "*The New NHS: Modern, Dependable*" This paper set out to create Primary Care Trusts (PCTs), Strategic Health Authorities (SHAs), the National Institute for Clinical Excellence (NICE) and the Healthcare Commission (Rogers, 2009). It also outlined the government commitment to supporting people with chronic conditions, and the subsequent DoH (2000) *NHS Plan, a plan for investment, a plan for reform,* made self-care one of five key building blocks of the new NHS.

A further publication in 1999 of the White Paper *Saving Lives: Our Healthier Nation* set out the government's plans for public health improvement and to save lives, promote healthier living and reduce inequalities in health (Taylor and Bury, 2007). This new approach of self-care has on one hand emphasised the challenge of managing chronic conditions; on the other hand, it noted that to face this challenge *"...everybody should try to look after themselves better, by not smoking, taking more exercise, drinking less and eating more sensibly..."* (DoH, 1999a:3).

On self-management, *Saving Lives* commented that *"people with long-term health problems such as diabetes, epilepsy or arthritis are skilled at recognising warning signs when their symptoms are getting worse"*, citing the arthritis care programme developed in the USA by Kate Lorig (DoH, 1999a:11), the idea of the Expert Patient was introduced (DoH, 1999b). While recognising the contribution this programme can make in improving the care of chronic conditions, it announced the establishment of a task force to design a new Expert Patient Programme (EPP) led by Sir Liam Donaldson (Kennedy et al, 2007). Sir Donaldson commented that in the past the 'wisdom and experience' of the patient had not been fully acknowledged by health professionals, and argued that EPPs will correct this failing, and that EPPs will become *'a centre piece of the NHS approach to chronic disease management in the 21st century'* (Donaldson, 2003:1). Soon after the publication of the findings of the Expert Patient task force, the EPP was established (DoH, 2001). Section (3.3) will examine this initiative in detail.

A subsequent publication that gave a direct link to the cost of health care service use was the Wanless Report (2002). This report marked out a 'fresh page' approach to the concordat between medical care, the patient and the state (Rogers et al, 2009). Wanless described three possible future scenarios of health care service use in light of the increased burden of chronic conditions, and argued that the *'Fully Engaged'* patient is the cheapest sustainable option (Wanless, 2002). The *'Fully Engaged'* scenario will be exemplified by a high level of public involvement and taking more control of their health and illness by better use of the health services (Wanless, 2002). He commented *"Fully engaged and active patients benefit not only as individuals. My inquiry showed that encouraging and supporting self-care was one of a number of actions which could potentially save the economy billions of pounds... patients remain far from fully engaged in their own care; opportunities are being lost and inequalities reinforced"* (Rogers, 2009; The Wanless Report, 2002:7).

The government responded to this report with a number of publications and initiatives that are increasingly focussed on self-management programmes and the care of people with chronic conditions (Abraham and Gardner, 2009). In 2004 the *NHS Improvement Plan* identified self-care as one of the new National Standards with almost 70-80% of patients with chronic conditions being helped by self-management programmes. The *Plan* stated that compared with other patients, Expert Patients report that their health is better, they can cope better with their condition, feel less limited in what they can do and are less dependent on hospital care (DoH, 2004). It set out the plan for the EPP to be rolled out by 2008 allowing thousands of people to take more control of their health and lives.

It was followed by another publication *'Self Care: A Real Choice'* (DoH, 2005). This paper highlighted self-care as one of the key building blocks for a patient-centred health service and as a key component of the collaborative model for supporting people with long term conditions. It reiterated that supporting self-care can improve health outcomes, increase patient satisfaction and help in deploying the biggest collaborative resource available to the NHS, patients and the public. This paper provided information for supporting self-care and the reasons why it is important, and suggested practical actions for health professionals providing self-care. It concluded that self-care represents an opportunity and challenge for the NHS to empower patients to take more control over their lives.

The key White Paper *'Our health, our care, our say: supporting people with long-term conditions to self-care'* followed in 2006 (DoH, 2006). It underlined the fact that the self-management of chronic conditions and the establishment of the EPP can be seen as part a wider policy framework for public health improvement and health service development. More recently the DoH (2011), in collaboration with the Expert Patient

Programme Community Interest Company (CIC), has developed a new tool that aims to stimulate demand for self-management courses that are both generic and disease specific.

3.3 Expert Patient Programme (EPP)

The EPP is explored throughout this Thesis and will be explicated primarily in chapter five. A detailed critique is developed in chapter six. Therefore, the purpose of this chapter is to trace the origins and the implementation of the EPP in the UK.

As noted before, the UK government has promoted the initiative of Expert Patient Programmes (EPP) as they recognised the necessity of self-management skills in treating people with chronic conditions (Amro et al, 2011a). As previously indicated in this Thesis the concept of an Expert Patient Programme was developed in the USA as the Chronic Disease Self-Management Programme (CDSMP) (Kennedy et al, 2007). The work of Halstead Holman and Kate Lorig at Stanford University, have shown how useful self-management skills and self-efficacy can be in maintaining and improving patients' health behaviour and health status, whilst lowering health care utilisation (Smeulders et al, 2007).

In 1978, Lorig and colleagues started to develop and evaluate programmes for people with chronic conditions (arthritis). They avoided the traditional model of professionals educating patients (Lorig et al, 1986). Using an innovative approach, Lorig trained lay volunteers that had chronic diseases with the skills to manage their own conditions (Squire and Hill, 2006). Her research demonstrated that six weekly education sessions lasting three hours, led by trained lay tutors, provided improvements in patients' communication skills with health professionals, symptoms and disease control and reduced healthcare service use. Against old comparisons, Lorig argued that the lay-led model was attractive because lay educators were plentiful and relatively cheap and could help other people with the disease by modelling self-care more effectively than healthy professionals (Lorig et al, 1999). Lorig found increasing evidence from research studies and from patients' associations that people have improved health and reduced incapacity if they take the lead themselves in managing their conditions with good support from the health services (Lorig et al, 1993).

Based on Kate Lorig's model, the EPP shared the assertion: that people with chronic conditions are well placed to know how to cope with their conditions (Griffiths et al, 2007). The DoH therefore, has set up the EPP task force with strong representation from voluntary sector organisations including the *Long Term Medical Conditions Alliance* and *Arthritis Care* who have run self-management skills training courses in the UK since the early 1990s (Rogers et al, 2009). Their contribution has been instrumental in promoting and disseminating the training, which formed the core of the EPP through a volunteer work force. In 2003, the EPP was established and promoted as a lay-led community-based (PCTs) chronic disease self-management programme involving two-to-three-hour six-weekly sessions led by lay volunteer tutors who themselves have a chronic condition (DoH, 2001). From 2003-2007 the EPP was piloted in about 98 per cent of Primary Care Trusts (PCTs) in which funding was received to train volunteer tutors and build networks round the country with the intention to widen access and make it available throughout the NHS by 2008 (Tyreman, 2005).

3.3.1 Lay-Led Vs. Professional-Led Programmes

Health systems are shifting to models of care that are inclusive of patient involvement in self-managing their own condition and health care. Lay-led self-management education programmes for people with chronic disease are considered an effective way to promote increased patient involvement (DoH, 2001). A Cochrane systematic review conducted by Foster et al (2009) could not find enough evidence to advocate one programme (professional versus lay led) over the other. Previous work by Lorig et al (1986) suggested no difference in outcomes between lay or professional-led programmes, but there was an obvious cost saving in lay-led self-management programmes.

The EPP developed in the UK has attracted considerable public support and publicity, and consumers recognise that such programmes have the potential to provide them with a voice and better health outcomes (Tyreman, 2005). There are uncertainties, however, about the effectiveness of lay-led self-management education programmes in different populations, in different health care settings, compared with professionally-led education programmes, and about the best modes of delivery (Griffiths et al, 2007).

The EPP is designed to enable active patient involvement, is generally well defined and has a pre-determined structure. EPPs are distinct from simple patient education, skills training or even peer support interventions (Kennedy et al, 2007). While interpretations of the term 'lay-led' may vary between different countries and different programmes, lay leaders are all trained and accredited and follow a self-management philosophy rather than a medical approach (Holman and Lorig, 2004). There are key differences between lay-led (or peer-led) education and professionally led education. Lay leaders commonly have a chronic disease and in disease-specific programmes they have the same condition; lay-led education may be less formal and facilitate more helpful discussion for participants; and lay-leaders may provide important and practical advice as they share their experience living with their condition (Lorig and Holman, 2003).

Much work has been undertaken in developing self-management skills for specific conditions and has resulted in a number of educational programmes led by professionals (Amro et al, 2010). These programmes aim to improve participants' adherence with condition specific regimens. Gibson et al (2002) argued there is evidence suggesting unless participants in such programmes are empowered to take control of aspects of self-management that are the traditional province of health professionals, this type of approach then does not necessarily lead to improved health outcomes.

The idea of empowerment and collaborative partnership as a vital element in patient self-management is the cornerstone of the EPP. Arguably, the most empowering aspect of the EPP is that it is not facilitated by a health professional but by a lay volunteer who has the same long-term conditions themselves (Wilson and Mayor, 2006). The support and advice is supplemented by the coaching role of an Expert Patient who has had some training in running the programme.

Having said this, Jordan and Osborne (2007) argued that contributing to the limited uptake of the EPP has been the lack of engagement by health professionals. Failure to effectively communicate with health professionals has resulted in difficulty in recruiting a sustainable number of participants and ensuring access for traditionally marginalised groups[1].

3.3.2 Generic Vs. Disease-Specific Programmes

In the past ten years, the EPP has been developed and evaluated as a generic programme that individuals with many different types of chronic conditions attend at the same time (Kennedy et al, 2005). Whether a disease-specific programme would have advantages over a generic programme remains an open question (Lorig et al, 2005). Evidence is lacking about which specific chronic diseases and in which population groups EPP's are most successful (Warsi et al, 2004). Jordan and Osborne (2007) claimed that trials have failed to provide convincing evidence of the generalisability of the CDSM and EPP. They argued that one generic programme for all conditions clearly has limitations and fails to utilise other interventions. Additionally, they added that such a generic programme often has a great under-representation of men and ethnic minorities and advocated for a flexible collaborative approach to both delivery and programme content (Jordan and Osborne, 2007).

The EPP in its generic form has targeted groups of patients with the most common conditions including: arthritis, asthma, back pain, diabetes, epilepsy, heart failure and multiple sclerosis, with an option of developing disease specific programmes in the future (DoH, 2001). However, Kennedy et al (2007) in the National Evaluation of the EPP commented that the generic form of the EPP has *"reinforced the value and salience of pre-existing self-care activities rather than initiating alternative behaviour change... so people who already saw themselves as good self-managers felt they had nothing new to learn"* (Kennedy et al, 2007:3).

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[1] As empowerment processes are fundamental to the concept of patients' participation and collaboration; particularly in self-management programmes, the EPP implemented in this study was committed to involving patients in designing and running the project. Therefore, lay volunteers who had a long history of living with COAG were trained and equipped to deliver this GEPP. I have had the role of liaising with health professionals running the clinics in terms of identifying participants who could benefit from the self-management programme.

Whilst one can argue that chronic conditions have many symptoms that are so much in common, some participants found the programmes not to be engaging as they did not include disease specific advice that they could relate to (Kennedy et al, 2007). It is noticeable, however, that chronic eye conditions are not included within the target groups at all. Patients with chronic eye conditions like COAG are facing far more challenges in their daily life.

3.3.3 Effectiveness of EPPs

Lorig's model of the CDSM was subjected to a number of evaluative studies including well-conducted randomised controlled trials (Rogers et al, 2009). Results suggest that this model could improve participants' health status, reducing hospital bed days and could be delivered effectively by lay volunteers. Lorig's et al's (1999) RCT also demonstrated significant improvement in self-rated health, pain, psychological well-being and significantly less health service utilization amongst the intervention group. Nonetheless, a further RCT with a longer follow up raised questions on the sustainability of the effects of such interventions.

Attracted by the success of the CDSM in the USA, Sir Donaldson asserted that the EPP would improve health status, slow the progression of diseases and reduce healthcare use (Donaldson, 2003). The DoH, with high expectations, has responded by investing £18 million so far in providing this programme across 300 PCTs in England (Griffiths et al, 2007).

With the great differences between the privately funded USA health care system, in comparison with state funded universally available on access NHS in the UK, questions were raised about the external validity of the self-management programmes developed in the USA (Taylor and Burry, 2007). With the lack of UK based evaluative studies to demonstrate its effectiveness, the DoH, through the National Primary Care Research and Development Centre in Manchester, decided to conduct a national evaluation of the EPP (Kennedy et al, 2007).

The evaluation examined two main components: running the self-management programmes and actions taken to mainstream the EPP within the NHS and link it to other programmes and initiatives involved in chronic condition self-management. The evaluation took the form of a six-month follow up randomised controlled trial to evaluate the patients' outcomes and its cost-effectiveness, patients' personal experience with undertaking the EPP and a process evaluation of its implementation by the PCTs (Kennedy et al, 2007) with 1000 participants from 245 EPPs.

The results were not as positive as they had hoped, as the EPP has been heavily promoted as a way of reducing the use of acute health services (Griffiths et al, 2007). There was a moderate increase in patients' self-efficacy, patients' confidence to change behaviour and their psychological health, and relatively small impact on the amount of energy people reported. However, there was no change in health service utilisation, the sum of General Practitioners consultations, practice nurse appointments, Accident and Emergency (A&E) Department attendances and outpatient visits (Kennedy, 2007). Further evaluative studies (Randomised Controlled Trials - RCTs) were also conducted and the results were even less glowing. Griffiths et al (2007) reviewed four UK based RCTs of lay-led self-management programmes (Barlow et al, 2000; Griffiths et al, 2005; Buszewics et al, 2006; Kennedy et al, 2007) which revealed little improvement in self-rated health and no decrease in the use of health care services.

The CDSM and, its English version, the EPP, were originally developed for use in heterogeneous patient groups assuming that patients with various chronic conditions can learn from each other as they have similar problems and needs (Wilson and Mayor, 2006). An extensive body of literature that supports the efficacy of self-management programmes that have been tailored to the particular needs of specific conditions has developed (Francis et al, 2007). Smeulders et al (2007) evaluated a disease specific EPP led by a team of lay volunteers and professionals for patients with an implantable cardiovascular defibrillator. The results were positive and promising, with improvement in general self-efficacy expectancies, symptoms of anxiety and QoL. Another self-management programme that is diabetes specific and has a focus on controlling symptoms has been delivered to newly diagnosed patients. It has been shown to be equally effective and shown significant improvements in patients' self-management behaviours and health outcomes (Skinner et al, 2003). Gifford and Groessl (2002) reviewed an HIV/AIDS self-management programme that also showed equally positive findings. Furthermore, Lorig's et al's (1999) arthritis self-management programme, which has a focus on strategies that are required for patients to deal with pain and consequences of disability, was impressive with its findings.

In their National Evaluation summary of EPP, Kennedy et al (2007) commented that there was a considerable demand for condition specific courses as participants expressed a need for specific condition information that was not included in the EPP in its generic form. They concluded that disease specific courses *"provide a closer fit with the way the NHS currently provides care i.e. the NHS distinguishes between conditions and a generic approach does not fit the current reality of the using services"* (Kennedy et al, 2007:4). In this context, Griffiths et al (2007) has offered an explanation as to why these programmes had more impact than the generic lay-led self-management programmes. They argued that these programmes are better targeted toward higher risk individuals who experience greater morbidity. A key feature of the success of these programmes was its correcting erroneous health beliefs and providing specific, clinical and relevant self-management plans for patients, and thirdly for cardiac and asthma programmes there was a structured exercise programme alongside the self-management advice (Griffiths et al, 2007).

A question yet to be answered is: To what extent chronic disease self-management programmes address health inequalities which arise when groups of people with reduced health status have needs which are not being adequately met? Generic programs are likely to meet the needs of those with sufficient personal, social and economic resources to make changes in their lives (Foster et al., 2009). It is understood that without targeting and adaptation for groups with low socioeconomic status, low levels of education, literacy or from different cultures, self-management programs are not likely to reach or engage disadvantaged groups. Therefore, an important consideration for the transferability of self-management interventions is how well they have been adapted in considering the social determinants of chronic disease self-management and how effectively they are able to meet the needs of specific disadvantaged groups (Swerisson et al, 2006). People from disadvantaged backgrounds are more frequently affected by chronic disease. Relevant social determinants of health include income and education factors including literacy, culture, and access to social support, employment and health services (Swerisson et al, 2006). Different cultural groups have diverse belief systems with regard to health and illnesses in comparison to the Western biomedical model of medicine. These belief systems may include different disease models and paradigms (e.g., Chinese medicine), various culturally-specific diseases and disorders, feelings about healthcare providers and seeking Westernized healthcare, and the use of traditional and indigenous healthcare practices and approaches (Vaughn et al, 2009). Helman suggests that people attribute causes of illness to: 1) factors within individuals themselves (e.g., bad habits or negative emotional states); 2) factors within the natural environment (e.g., pollution and germs); 3) factors associated with others or the social world (e.g., interpersonal stress, medical facilities, and actions of others); and 4) supernatural factors including God, destiny, and indigenous beliefs such as witchcraft or voodoo (Helman, 2001). While westerners tend to attribute the cause of illness to the individual or the natural world whereas individuals from non-industrialized nations are more likely to explain illness as a result of social and supernatural causes (Vaughn et al, 2009).

In countries like the UK, healthcare is widely accessible by all regardless of income level or insurance status. Many aspects of culture can affect successful and effective treatment approaches including religion and spirituality, social support networks, beliefs and attitudes about causes and treatments, socioeconomic status, and language barriers (Matsumoto and Juang, 2008). There is no one perfect program that is culturally relevant for all involved; however, approaching self-management programmes from a culturally competent perspective should be paramount.

3.3.4 Cost Effectiveness of EPPs

Promoting effective self-management skills is an important factor in providing a patient-centred health care service (DoH, 2000). With providing self-care support to any patient with a chronic condition as the main aim; the EPP will have targeted over 100,000 people in England by 2013. In the literature there is a large and expanding number of studies suggesting the effectiveness of self-management programmes in chronic conditions, however, little of this evidence addresses the cost effectiveness of these interventions (Wheeler et al, 2003). In a budget-constrained NHS, it is important that the EPP is cost-effective as well as clinically effective.

Richardson et al (2008) conducted a RCT to assess the cost effectiveness of EPPs compared to a treatment as usual alternative. The results of this study were consistent with the evaluation of the CDSM based in the USA. In comparison with the usual treatment a lay-led self-management programme is likely to improve patient outcome with little impact on cost; therefore, it provides a cost-effective use of scarce resources (Richardson et al, 2008).

3.3.5 A Paradox of Patient Empowerment and Medical Dominance

The importance of self-management in reducing the burden of chronic conditions is increasingly recognised and becoming evident in health policy (Kennedy et al, 2005). Initiatives like the EPP have been promoted widely as part of long-term condition strategies. It recognises the role of patients in managing their conditions in a way that empowers them and promotes a sense of wellbeing (Wilson et al, 2007). Drawing upon Bandura's self-efficacy theory (Bandura, 1986), if individuals feel confident that they can control their chronic conditions, the likelihood is they will be able to do so. However, despite it being led by lay volunteers, Wilson (2002) suggested that there is a number of underlying power issues within the EPP and the paternalistic health care service that have the potential to inhibit any sense of empowerment.

Within the EPP, it was argued that power may be withheld from Expert Patients and participants in three ways (Gilbert, 2005). Firstly, patients may feel obliged to enrol in the EPP as suggested by health professionals. Secondly, participants accept the self-management practices taught because the EPP may create benefits or bring an affirmative award. Finally, the EPP operates in an environment where self-management is not only seen as a right but also as a responsibility. Furthermore, Fox et al (2005) expressed similar views and questioned whether all patients actually want to participate in self-management programmes like the EPP.

The paternalistic approach to chronic conditions health care where health professionals make all the decisions about treatment and closely monitor the patient's progress is considered inappropriate in modern healthcare (Holman and Lorig, 2000). Instead, when health professionals engage in effective communication and support decision making and self-management actions they are enabling patients to optimally manage their conditions outside of the health service setting (Kennedy et al, 2005). Within the context of the EPP, Davidson (2005) identified the potentiality of an EPP reinforcing the medical paradigm rather than empowering participants. An analysis of the EPP policy by Wilson et al (2007:434) suggested that *"it had a Foucaldian potentiality of medicalising self-care practices within an individual's previously hidden home life".* Fox et al (2005) observed the EPP has been linked with the continuing language of disease and paternalism still present within the programme and questioned whether the EPP can empower patients when so heavily reliant on the medical model. A study by Wilson et al (2007) has echoed this concern as they indicated the EPP course content serves to reinforce an image of the Expert Patient as defined by the medical paradigm; however, they recognised a movement triggered by the EPP that has the potential to make a change within the NHS structure.

Whilst not undermining the success and the potential of the EPP as a life-changing event (EPP, 2006) and its effectiveness in empowering participants (Barlow et al, 1998), the question remains whether this empowerment remains at the individual level or has developed at a community level with the potential of challenging the paternalistic structures of current practice.

3.4 Theoretical Underpinning of Self-Management and Adherence

In Chapter Two the changing terminology of compliance, adherence and concordance was examined. Based on the perspective presented in Chapter Two and the terminology used at Moorfields Eye Hospital NHS Foundation Trust in reference to patient behaviour toward medication use, the word "adherence" will be used throughout this section. Theories that explain the constructs of adherence will be examined in this section as well.

Theories are essential in promoting an understanding of human behaviour, directing research and facilitating transferability from one health issue, geographical area or health care setting to another (Michie, et al., 2005). However, early programmes that are related to self-management of different chronic conditions often lacked an explicit theoretical basis. In COAG, the problem of adherence remains a challenge for the medical professions and social scientists. Therefore, this section will provide a critique of the major theories that explain human behaviour and adherence while outlining an alternative theory model that provides a contrasting framework to underpin self-management and adherence in a glaucoma context.

A review by Munro, et al. (2007) examined the empirical evidence and theories applied in changing behaviour interventions in relation to long-term disease self-management and treatment regimen adherence. This review revealed that certain theories have the potential to both improve understanding of behaviour change and contribute to the design of more effective interventions that promote collaborative partnerships and adherence. Several interventions have been designed to improve patients' treatment adherence, but few theories describe the processes involved in doing so (Michie, et al., 2005; Olthoff et al, 2005). With more than 30 theories of health behaviour change available, choosing the most appropriate theory when designing an intervention is far from an easy task (Munro, et al., 2007). This is particularly problematic in the field of adherence to long-term medications, such as medications required to manage COAG where the cost of non-adherence is quite severe with an ultimate eyesight loss.

Leventhal and Cameron (1987) initially classified five theoretical perspectives related to long-term treatment adherence: (1) Biomedical; (2) behavioural; (3) communication; (4) self-regulatory and (5) cognitive perspective. Recently a sixth domain, stage perspective, has emerged. Each perspective includes several theories, where the most commonly used theories are those within the cognitive perspective and the transtheoretical model of the perspective stage (Redding et al., 2000). Each of these perspectives will be reviewed in the narrative that follows.

3.4.1 Biomedical Perspective

Patients in this perspective are viewed as a passive recipient of the doctors' instructions, where patients who fail to adhere is understood to be caused by patient characteristics like age and gender (Blackwell, 1992). Technological innovations to monitor adherence to medications, such as the "Unobtrusive eye drops monitor" are rooted in this perspective.

A fundamental limitation of this perspective is that it fails to consider factors other than patient characteristics that may affect their health behaviours (WHO, 2003), for example, patients' perspectives of their own illness; psycho-social factors; socioeconomical; environmental; and/or demographic factors. An attempt to incorporate these factors with the biomedical perspective produced a more integrated theory, the "bio-psycho-socio-environmental" theory, in which they attempted to consider the wider socio-environmental context (Ross and Deverell, 2004).

However, the assumption that patients are passive recipients, while placing a greater emphasis on biomedical factors made this theory less popular and unlikely to significantly improve glaucoma patient medication adherence. Patients nowadays are more active and want to be part of decision-making; no longer receive and follow instructions passively. Van Dulmen et al (2007) commented that in spite of the many advances in adherence and adherence research amongst glaucoma patients, non-adherence rates have remained nearly unchanged in the last decade. They concluded that these interventions and theories adopted by and large belong to this perspective, have failed to predict and explain non-adherence adequately.

3.4.2 Behavioural Perspective

This perspective includes behavioural learning theory (BLT) that focuses primarily on environmental factors as well as the teaching of skills to manage adherence (WHO, 2003). The likelihood of a patient following a specific behaviour will partially depend on internal (thoughts) and external factors (environmental cues), while consequences in the form of punishments or rewards will discourage or encourage such behaviour respectively as illustrated in Figure 3.1.

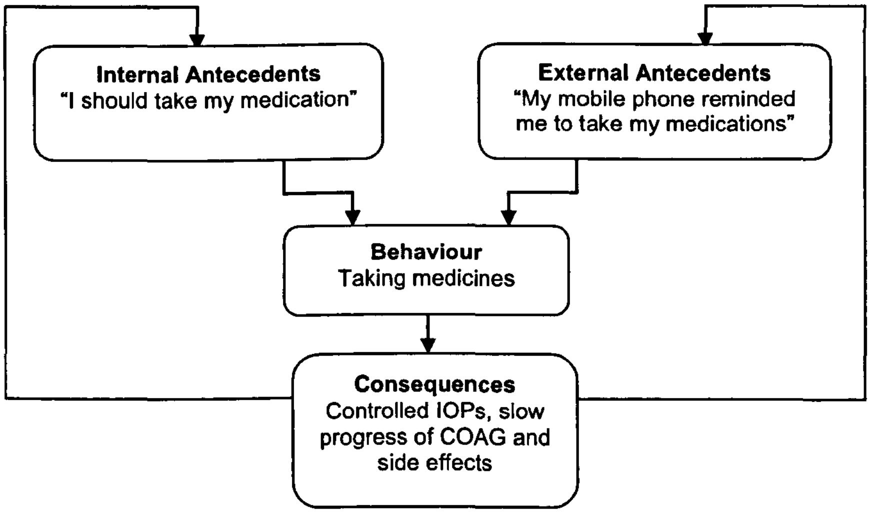


Figure (3.1): Behavioural Learning Theory.

Glaucoma adherence interventions of this theory tend to break down the complex behavioural changes into small steps that can be sequentially learned and reinforced by external reminders. Munro et al (2007) claimed that glaucoma interventions that are informed by this perspective such as patient reminders have been found to influence health behaviours and improve adherence. A meta-analysis conducted by Simoni et al. (2006) examining adherence to therapy concluded that interventions with cue dosing and external reward approaches derived from BLT were as effective as those without. Blackwell (1992) criticises BLT for lacking an individualised approach and for failing to consider factors that are not linked to immediate rewards but are influential to health behaviour change including past behaviour; habits; or lack of acceptance of the diagnosis. This perspective has also been criticised for regarding patients as passive and failing to consider patient empowerment.

3.4.3 Communication Perspective

Communication is understood to be *"the cornerstone of every patient-practitioner relationship"* (Ross and Deverell, 2004:56). This perspective suggests that improving communication between health professionals and patients will improve adherence, which can be achieved through patient education and health professional communication skills (Ross and Deverell, 2004). An example of an intervention informed by this perspective is one that aims to improve patient-professional interaction placing emphasis on the timing of the treatment, instruction and comprehension (Munro et al., 2007).

Reviewers examining the effects of interventions including communication elements have rarely examined the effects of communication on health behaviours specifically (Lewin et al., 2001). In relation to this, two reviews showed that improved communication interventions led to improved communication in consultations, improved patient satisfaction with care and improved health outcomes (Lewin et al., 2001). However, these reviews also show limited and mixed evidence on the effects of such interventions on patient health care behaviours such as adherence (Munro et al., 2007).

A more recent study conducted by Friedman et al (2008) explored doctor-patient communication and its effect on glaucoma adherence. The findings supported the importance and the association between effective doctor-patient communication and improved adherence levels. The limitation of this perspective is that it fails to acknowledge attitudinal, motivational and interpersonal factors that might influence the reception of the information and its translation into behaviour change (Blackwell, 1992).

3.4.4 Self-Regulation Perspective

This perspective proposes that it is necessary to examine an individual's subjective experience of health threats to understand the way in which the individual adapts to these threats (Leventhal et al, 1992). According to this theory, individuals' illness representations of health threats that combine new information with past experience are key determinants of their behavioural and emotional response to illness (Edgar and Skinner, 2003). These representations guide their selection of particular behaviours for coping with health threats and consequently influence associated outcomes. This process of creating health threats and choosing coping strategies is assumed to be dynamic and informed by the individual's personality, religion and socio-cultural context (Leventhal et al, 1992). Skinner et al (2003) identified five core elements that form our illness representation as illustrated in the following table:

Table (3.1): Core elements of illness representation

1. Identity: What is glaucoma? What symptoms are experienced? What is actually wrong?
2. Cause: What caused my glaucoma?
3. Timeline: How long will it last?
4. Consequence: How will glaucoma affect me now and in the future?
5. Treatment effectiveness: How good is my treatment at controlling or curing my glaucoma?

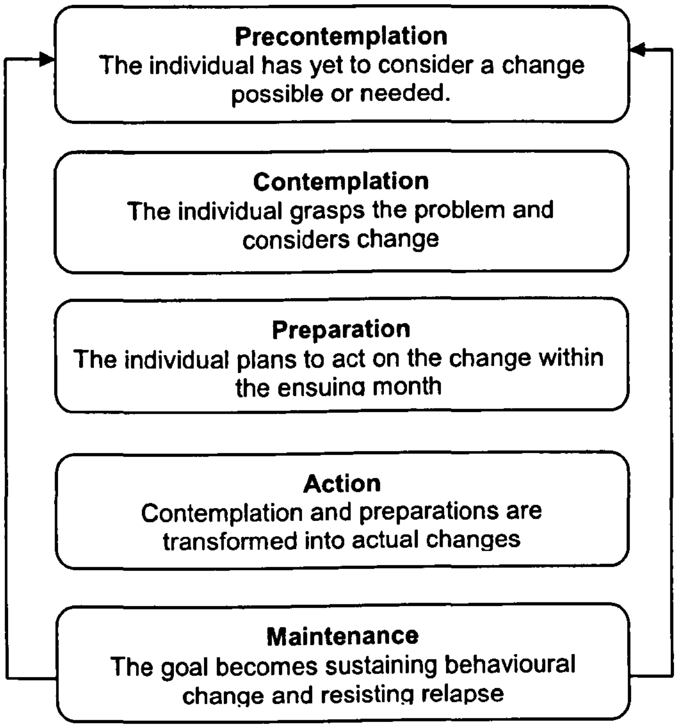
Munro et al. (2007) suggested that this theory offers little guidance to the design of the interventions. With no meta-analysis available to examine its effectiveness, specific suggestions are still required as to how these processes could promote adherence.

3.4.5 Cognitive Perspective

The cognitive perspective includes theories such as the health belief model (HBM), social cognitive theory (SCT), the theories of reasoned action (TRA), the theory of planned behaviour (TPB), the protection motivation theory (PMT) and the information-motivation-behaviour skills (IMB) model (which will be discussed in Section 3.4.6.5). These theories share the assumption that attitudes and beliefs as well as expectations of future events and outcomes are major determinants of health related behaviours (Stroebe, 2000). They focus on cognitive variables as part of behaviour change and so propose that individuals will choose the action that most likely will lead to positive outcomes (Gebhardt and Maes, 2001). Munro et al (2007) argued that these theories have major weaknesses including: failing to address the behavioural skills needed to ensure adherence as well as giving little attention to the origin of beliefs and how they may affect other behaviours. Furthermore, it has been argued that these theories have failed to recognise the impact of other factors that may compromise adherence behaviour, such as power relationships and social reputation (WHO, 2003). As this research is based on the components of the cognitive perspective, it therefore warrants a detailed discussion.

3.4.6 Stage Perspective

This perspective includes the transtheoretical model (TTM) as its main theory. This theory hypothesise a number of different, discrete stages and processes of change, and reasons that people move through, relapse and revisit earlier stages before success is achieved (Sutton, 1997). This model assumes that health behavioural changes are the result of a logical process, divided into five stages as illustrated in Figure 3.2.



Precontemplation
The individual has yet to consider a change possible or needed.

Contemplation
The individual grasps the problem and considers change

Preparation
The individual plans to act on the change within the ensuina month

Action
Contemplation and preparations are transformed into actual changes

Maintenance
The goal becomes sustaining behavioural change and resisting relapse

Figure (3.2): Transtheoretical Model: Adapted from Sutton (1997).

This theory has received criticism. According to Bandura (2004) this theory violates the three basic assumptions of stage theories. Bandura suggested that human functioning is too multifaceted to fit into separate and discrete stages. While Munro et al. (2007) praised TTM as a popular theory amongst practitioners; it has received little direct research support for its efficacy. The meta-analysis identified for this review did not offer direct support for this theory while another review identified that interventions that used the stage perspective were no more efficient than those not using the theory (Marshall and Biddle, 2001). In a glaucoma context, the barriers to adherence according to this theory are 'temptations' and the question framed here is: How tempted can an individual be to engage in an unhealthy behaviour across different challenging situations?

3.4.6.1 Health Belief Model

Whilst a range of other theories attempts to explain health behaviours and service utilisation, significant attention has been paid to this model in relation to self-management (Hassell et al, 2000). This model considers health behaviour change as a rational appraisal of the balance between the barriers to and benefits of the action and the change as a whole (Blackwell, 1992). As illustrated in Figure 3.3, the individual's readiness to take a particular course of action is influenced by perceived risks and benefits from taking these actions which will be influenced by an individual's view of the seriousness of the condition, internal and external cues, self-efficacy and lastly modifying factors such as culture and gender (Hassell et al, 2000).

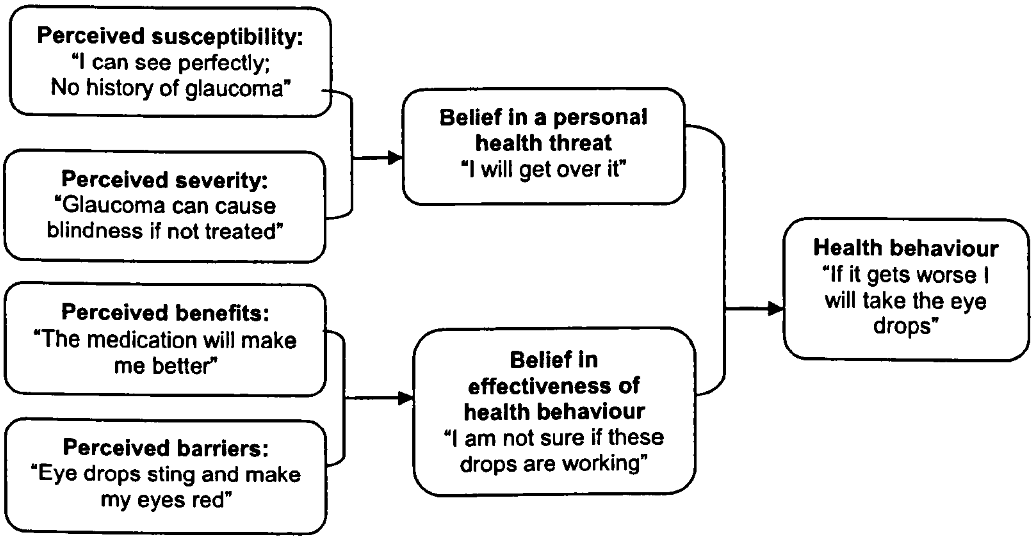


Figure (3.3): Health Belief Model: Adapted from Stroebe (2000).

According to this model, demographic and socio-psychological and cultural variables influence both perceived susceptibility and perceived seriousness, and the perceived benefits and perceived barriers to change (Strecher and Rosenstock, 1997). Therefore, high perceived threat, low barriers (i.e. side effect) and high perceived benefits to a certain action will increase the likelihood of the patient engaging in that action. In more simple glaucoma terms, if the health professional engages in a discussion with a glaucoma patient and explains the pros and cons of the condition, followed by the patient's decision regarding the treatment, the likelihood that this patient will adhere to his or her treatment regimen is very high. However, this model has been extensively criticised in failing to; first, provide significant correlation between health beliefs and professionally set self-care (Roberson, 1992) and second, determinants of health behaviours such as positive effect of negative behaviours and social influence are not included (Stroebe, 2000). While the HBM has insufficient explanatory power in self-management and adherence, social cognitive theory;

particularly self-efficacy, appears to provide a prediction of self-care (Strecher et al, 1986).

3.4.6.2 Social-Cognitive Theory

Unlike earlier chronic disease self-management programmes, Lorig's CDSM has a very clear theoretical model which is based on Bandura's social cognitive theory of behaviour. Lorig (1986) stated that the key predictors of successful behaviour change are confidence (self-efficacy) in the ability to carry out an action and expectation that a particular goal will be achieved. When patients succeed in resolving problems, which they have themselves identified, it enhances their sense of self-efficacy (Bandura, 1977). This theory evolved from social learning theory and may be the most comprehensive theory of behaviour change developed so far (Redding, et al., 2000). It hypothesizes a multifaceted causal structure in the regulation of human motivation, action and wellbeing as well as offering predictors of adherence and guidelines for its promotion (Bandura, 2000). While knowledge of health risks and benefits are prerequisites to health behaviour change, according to this theory, additional self-influences are necessary for change to occur as illustrated in Figure 3.4.

A person's beliefs regarding self-efficacy and abilities to self-manage their condition are among some of these influences, and they play a central role in behaviour change (Bandura, 2004). In summary, this theory proposes that behaviour change occurs if people perceive that they have control over the outcome, that there are few external barriers and that individuals have confidence and self-efficacy in their ability to execute the behaviour (Armitage and Conner, 2000). Nevertheless, Taylor and Burry (2007) argued that the extent to which self-efficacy is in fact a significant independent variable relating to self-management and adherence capabilities in the overall population remains unclear. They suggested that the degree to which high levels of observed self-efficacy are a direct cause, rather than a consequence of coping well with a chronic disease is also unclear.

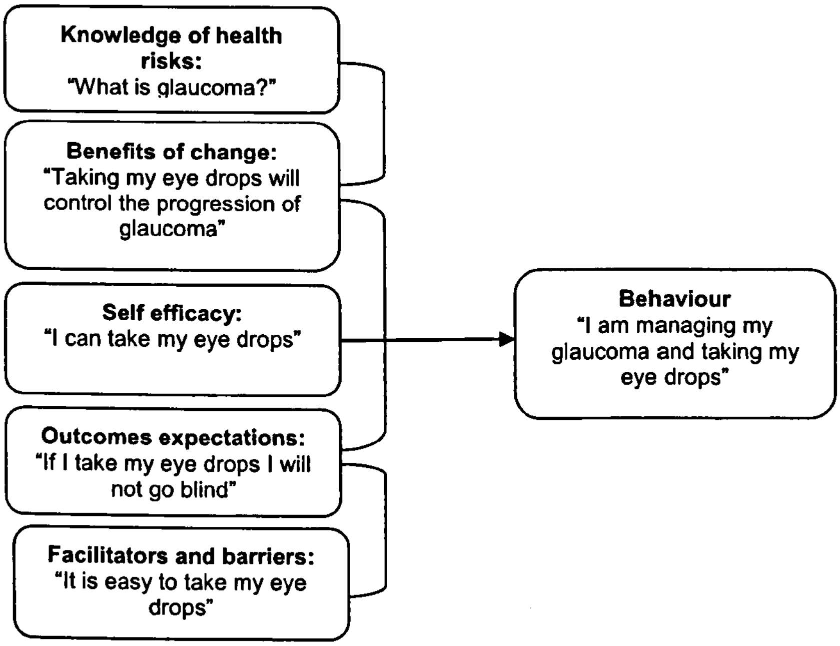


Figure (3.4): Social Cognitive Theory: Adapted from Bandura (2000).

Kalichman et al (2002) commented that self-efficacy serves as a proxy to behavioural skills and may not be as predictive of adherence to medication as a direct observational skill assessment. Stone (1999) criticised the wide ranging focus of this theory, and observed that this theory is often used only in parts due to difficulties in operationalising its components; thus raising questions regarding its applicability to intervention development.

3.4.6.3 The Protection-Motivation Theory

Health behaviour change according to this theory can be achieved by appealing to the patient's fears. Three components of fear arousal are suggested as illustrated in Figure (3.5): the magnitude of harm caused by the event; the probability of that event occurring; and the efficacy of the protective response (Rogers, 1975). This is the only theory within the cognitive perspective that explicitly uses the costs and benefits of existing and recommended behaviour to predict the likelihood of change (Gebhardt and Maes, 2001). This model may be appropriate for adherence interventions, as individuals do not consciously re-evaluate their routine behaviours such as taking long-term medication. However, the impacts of social, psychological and environmental factors on motivation require further consideration (Floyd, et al, 2000).

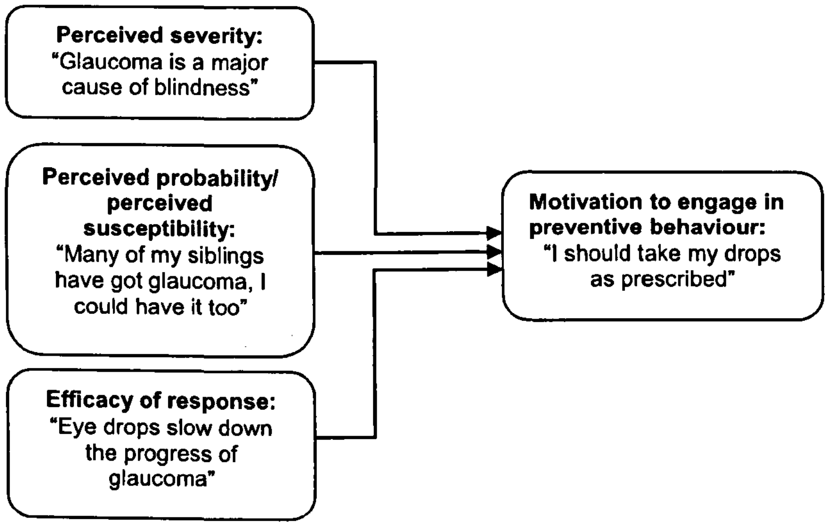


Figure (3.5): Protection-Motivation Theory: Adapted from Rogers (1975).

3.4.6.4 Theory of Reasoned Action (TRA) and the Theory of Planned Behaviour (TPB)

According to the TRA and TPB, most socially relevant behaviours are under volitional control, and that a person's intention to perform a particular behaviour is both the immediate determinant and the single best predictor of that behaviour (Sutton, 1997). Subsequently, a person's intentions to perform behaviour are determined by their attitude and positive and negative beliefs of the outcomes of the behaviour. Behaviour is also influenced by subjective norms, including perceived expectations of important others, and the motivation for a person to comply with others' wishes. Sutton (1997) suggested that TRA and TPB require more conceptualisation, definition and additional explanatory factors. Stroebe (2000) argued that these theories are largely dependent on rational processes and do not allow explicitly for the impact of emotions and religious beliefs on behaviour.

3.4.6.5 Information-Motivation-Behavioural Skills (IMB) Model:

Grounded in health and social psychology, the IMB model asserts that self-management and adherence as a health behaviour are determined principally by individuals' relevant information (knowledge), attitudes toward following treatment regimens (motivation) and abilities to perform necessary adherence and self-management tasks together with a sense of self-efficacy (Behavioural skills). As illustrated in Figure 3.6, these constructs are essential prerequisites for behavioural change but not necessarily sufficient in isolation (Fisher and Fisher, 1992).

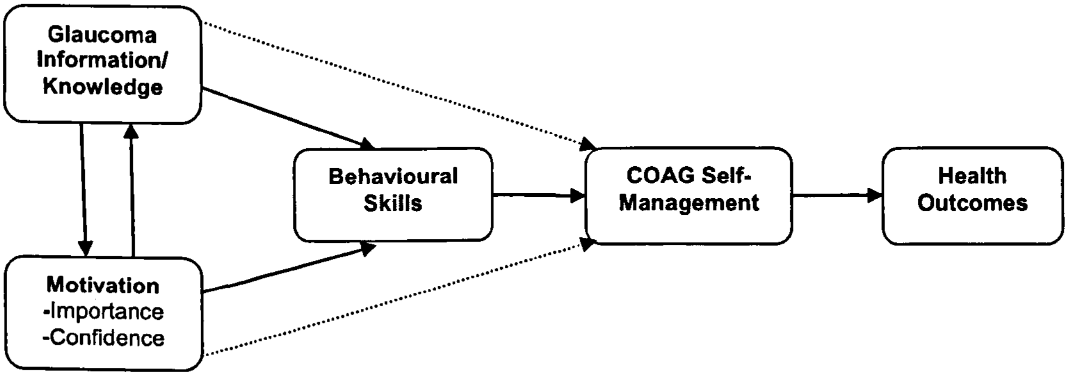


Figure (3.6): Contribution of information, motivation, and behavioural skills to COAG self-management and health outcomes: Adapted from Fisher et al. (2003).

The IMB model was originally constructed to be conceptually based, generalisable and simple to promote contraceptive use and prevent HIV transmission (Fisher et al., 2003). Subsequently, it has been tailored and applied to numerous health promotion behaviours, with particular attention to adherence for treatment regimens in chronic conditions (Fisher and Fisher, 1992). Kalichman et al (2006) empirically examined the associations between the constructs of this model in changing behaviour. They commented that the IMB model is particularly interesting because of the intuitive appeal that behaviour change requires; knowledge of the health implications of behaviour, the need to enhance motivation for behaviour change, and the requisite skills needed to enact behaviour change.

The IMB model is the only theory of this category that recognises the necessity and importance of a set of behavioural skills in initiating a positive self-management skill. Furthermore, it has other applications in health behaviour change as it provides a conceptual basis for analysis and insight into the determinants and dynamics of adherence to medical treatment behaviours (Fisher et al., 2006). These two main advantages make this model particularly interesting and therefore adopted for this study.

3.5 Theoretical Underpinning of COAG Self-Management and Adherence

As noted previously, there are over 30 psychological theories of behaviour change which are often fragmented with a contradictory evidence base and lacking a rigorous test to advocate one over the other. With the lack of published comparisons between theories to long-term adherence, it is vital to ensure the applicability of a chosen theory in the research context. Given the complexity of self-management and adherence behaviours to treatment in COAG (Stryker et al, 2010), applying the appropriate theory helps understand and conceptualise this problem. Many interventions to improve adherence in chronic conditions are unsuccessful and sound theoretical foundations are lacking (van Dulmen et al, 2007).

In this section, the IMB framework is employed to demonstrate the determinants of self-management amongst patients with COAG. The approach followed is collaborative in the sense that self-management is a collaborative effort where patients, providers and the service provided all contribute collectively. The success or failure of this effort depends on how well the collaboration works. This model has not received attention in chronic eye disease self-management; however, it has a considerable relevance to chronic disease management and adherence behaviours (HIV/AIDS viral therapy) (Amro et al, 2010). Bearing in mind the uniqueness of the needs of patients with COAG; given this research is an action research study, it was imperative to gain a working knowledge of the validity of this model in an ophthalmic context and how to employ this model to meet the needs and expectations of glaucoma patients.

Ware et al (2006) argued that models developed for use in a particular socio-cultural context cannot simply be assumed to be valid in another. They lay out a schema of 4 analytic questions that assesses the IMB model validity in the new context. These questions will be explored to examine the validity of this model in a glaucoma context in the following narrative:

Q1: Are the model's basic concepts relevant to the new setting?

An important indicator of relevance of these concepts is its representation in the experience of patients involved. During the observation period of this study, patient interviews and observations were conducted. Information was represented in patients' views as a basic understanding of their condition, treatment options, and prognosis of the condition and treatment side effects. Other statements of their commitment to taking their medication, confidence in the effectiveness of these medications and anticipated benefits of taking the treatment testified the motivational aspect of this model. Another common statement expressed by patients was whether they were instilling their drops correctly and timely, in addition to strategies followed to remind them of using these drops, which demonstrated mastery of adherence-related behavioural skills.

Q2: Are basic concepts important to the new setting represented in the model? This question addresses whether new concepts should be added to this model. Answering this question requires appropriate understanding of the setting to be used in which to identify basic concepts of validity required but not presently included in the model. Two conceptual domains are particularly relevant and might increase the validity of this model, the social context and the cultural context.

The social context here represents the organisation of social relations and interpersonal ties. Social structural barriers to adherence, i.e., family and significant others influence, do not appear in this model, or rather appear as a moderate influence, but they are considered to be of relevance in glaucoma adherence. As the majority of glaucoma patients are senior adults, inevitably they will rely on family members, friends and/or carers for support.

The cultural context represents a set of norms, values, religious, ethical and meanings that shape an individual's behaviour and helps to make sense of experience. Culture as part of any society or community plays a role in shaping glaucoma adherence; yet culture does not figure in the IMB model. This was represented in a particular case where a young glaucoma patient in his twenties refused taking any eye drops or accepting the diagnosis, and insistence on the part of the young man that *"if I have a problem with my eyes the cure will come from GOD, not eye drops"*, and that he will seek the help of his church instead.

Q3: Are the meanings of the model's basic concepts accurate for the new setting?

This question focuses on the indicators through which basic concepts in a model are specified. For example, the ability to perform necessary adherence skills is one indicator of the concept of behavioural skills. The use of reminders and cues is a relevant example that has been used extensively in glaucoma treatment. Socio-cultural differences were present at this indicator level; for instance, a Muslim patient indicated the scheduled time of the morning prayers and evening prayers for taking his eye drops. Dinner preparation was relevant to other patients.

Q4: Does the model capture the complexity of adherence and self-management in the new setting?

As noted earlier, the challenge of adherence and self-management in glaucoma is widely acknowledged to be complex with many barriers and facilitators. The idea of developing a valid theoretical model of adherence offers a new opportunity to capture this complexity. The following section will examine the constructs of this model.

3.5.1 The Construct of the IMB Model

As noted above, knowledge, motivation and behavioural skills are the main constructs of this model. Though essential prerequisites for behavioural change, they are not necessarily sufficient in isolation.

3.5.1.1 Knowledge

Past research has shown that information alone is an inconsistent predictor of health behaviour. However, when evaluated as part of the IMB model, information has been a consistent predictor of health behaviour (Anderson et al, 2006). To manage their condition, patients with COAG need knowledge, including basic information about their condition, screening, diagnosis, prognosis, treatment options and what they can do to maintain their vision and control their glaucoma. They need a clear understanding of their personal ophthalmic history, the treatment they are taking and why they are given this treatment, as this knowledge will serve as guides for personal actions. These are the main prerequisites for strong concordance as will be explicated later.

Stryker et al (2010) in their study observed that half of the participants were looking for information about their glaucoma. However, non-adherent participants were less likely than adherent participants to feel that they understood all the information they had received about their eyes. They also need to know how to contact health care professionals, ask questions and access care. However compelling and necessary information provision may be, information alone is usually insufficient to bring about changes in self-management behaviours; particularly as it relates to adherence and concordance.

3.5.1.2 Motivation 'Improving Adherence with Medication'

The second component, motivation, results from attitudes and beliefs about outcomes of adherent behaviour; significant others' support for the behaviour; and the patient's subjective perception of how patients with glaucoma might behave. According to this framework, motivation or readiness to change or sustain behaviour can be conceptualised as having two main components, both relevant to self-management approaches in chronic illnesses: *importance* and *confidence* (Fisher, et al, 2006). Patients may be aware of the need for consistent use of the anti-hypertensive eye drops and they may consider this treatment as very important. However, Fisher et al (2003) pointed out that if the patient is lacking confidence they can manage side effects, remember dosing times and use medications appropriately but overall motivation will be weak. Conversely, other patients may be highly confident that they have the skills, support and tools to take their medications consistently, but they may not see the importance of doing so. In both cases, the patients are unsure about changing as they lack motivation, but for different reasons. Self-management approaches to each one should be targeted differently.

3.5.1.3 Acquiring Necessary Behavioural Skills

For information and motivation to translate into strong self-management, most patients require concrete behavioural skills that can be learned, practiced and adapted to environmental resources and constraints (Fisher et al., 2006). These skills may be very specific technical skills, (such as instilling eye drops or using a drops reminder or cues), or may be broad self-management skills, (such as how to make an action plan to achieve a goal, how to communicate effectively with health professionals or how to find resources and social support). This conceptual framework suggests that behavioural skills are likely to be applied when they are practical and effective in addressing patients' most compelling disease management priorities (Fisher and

Fisher, 2000). According to this theory, a patient's satisfaction with the care they receive improves as the patient's sense of ownership and empowerment grows as a direct result of addressing the three main determinants of health outcomes. Moderating factors affecting adherence include psychological health, an unstable living situation, poor social support, and poor access to medical care. Although not developed to describe, predict, or influence glaucoma self-management behaviours, the IMB model has strong implications for enhancing chronic disease self-management and adherence behaviours (Amro et al, 2011a). The following section will explicate this adherence model.

3.5.2 The Adherence Model for the Glaucoma Expert Patient Programme

Adherence to long-term intraocular pressure (IOP) lowering medication is poor in patients with glaucoma, which is a significant factor in disease progression. Therefore, any educational or self-management programme for patients with COAG should address the issue of adherence to treatment regimens. Building on the Fisher et al (2003) IMB model, Starace et al (2006) developed the IMB model of adherence. This model demonstrates that adherence to a medical regimen has much in common with other complex health behaviours; therefore, adherence will occur as a function of the presence of a set of relevant information, motivation, and behavioural skills factors as illustrated in Figure 3.7 (Fisher et al, 2003).

According to this model adherence-related information is an essential prerequisite for consistent adherence and includes accurate information regarding one's specific regimen, potential drug interaction and side effects. Personal motivation includes the patient's attitude and beliefs toward potential outcomes and suboptimal adherence, whereas social motivation includes the patient's perception of support for adherence behaviours from significant others' wishes. Subsequently, glaucoma patients who are well informed about their condition, motivated to act, and possess the requisite behavioural skills to act effectively are more likely to adhere to treatment regimens and reap substantial health benefits. Conversely, patients who are poorly informed, unmotivated to act, and lack the requisite behavioural skills for effective adherence will likely be non-adherent to treatment regimens and will fail to realise its health benefits.

Although this model provides a good understanding of patients' behaviours regarding adherence, the relationship between adherence-related information and motivation is not assumed in this model. For example, there are cases where motivation does not imply correct information (e.g., the patient may be highly motivated to follow what he or she understands to be his or her prescribed treatment regardless of whether that understanding is accurate), nor does accurate information imply high motivation (e.g., one may be entirely accurate in understanding the requirements of his or her treatment regimen and still feel unmotivated to fulfil those requirements) (Starace et al, 2006). According to this model, adherence behavioural skills include both objective ability and perceived self-efficacy for performing critical adherence-related skills. Examples of this include acquiring and self-administrating medications, incorporating treatment regimens into daily life, minimising side effects, seeking out new information when needed, and developing self-reinforcement strategies for establishing and maintaining adherence (Rollnick et al., 2000).

As illustrated in Figure 3.7, behavioural skills are directly related to adherence behaviour, whereas adherence-related information and motivation are related to adherence behaviour primarily through behavioural skills. Specifically, the IMB model of adherence predicts that, to the extent that the skills required for adherence behaviour, behaviour skill will mediate the relationship between information and motivation and adherence behaviour (Fisher et al., 2003). Consistent with the available literature, the IMB model of adherence predicts that high levels of adherence will result in favourable health outcomes and that poor adherence will result in unfavourable health outcomes. Moreover, the model assumes that favourable or unfavourable health outcomes will affect subsequent levels of adherence-related information, motivation, and behavioural skills through a feedback loop (Fisher and Fisher, 1992). Finally, the model identifies several potential factors that may moderate (strengthen or weaken) the relationship between adherence-related information, motivation, behavioural skills, and adherence per se (Starace et al, 2006).

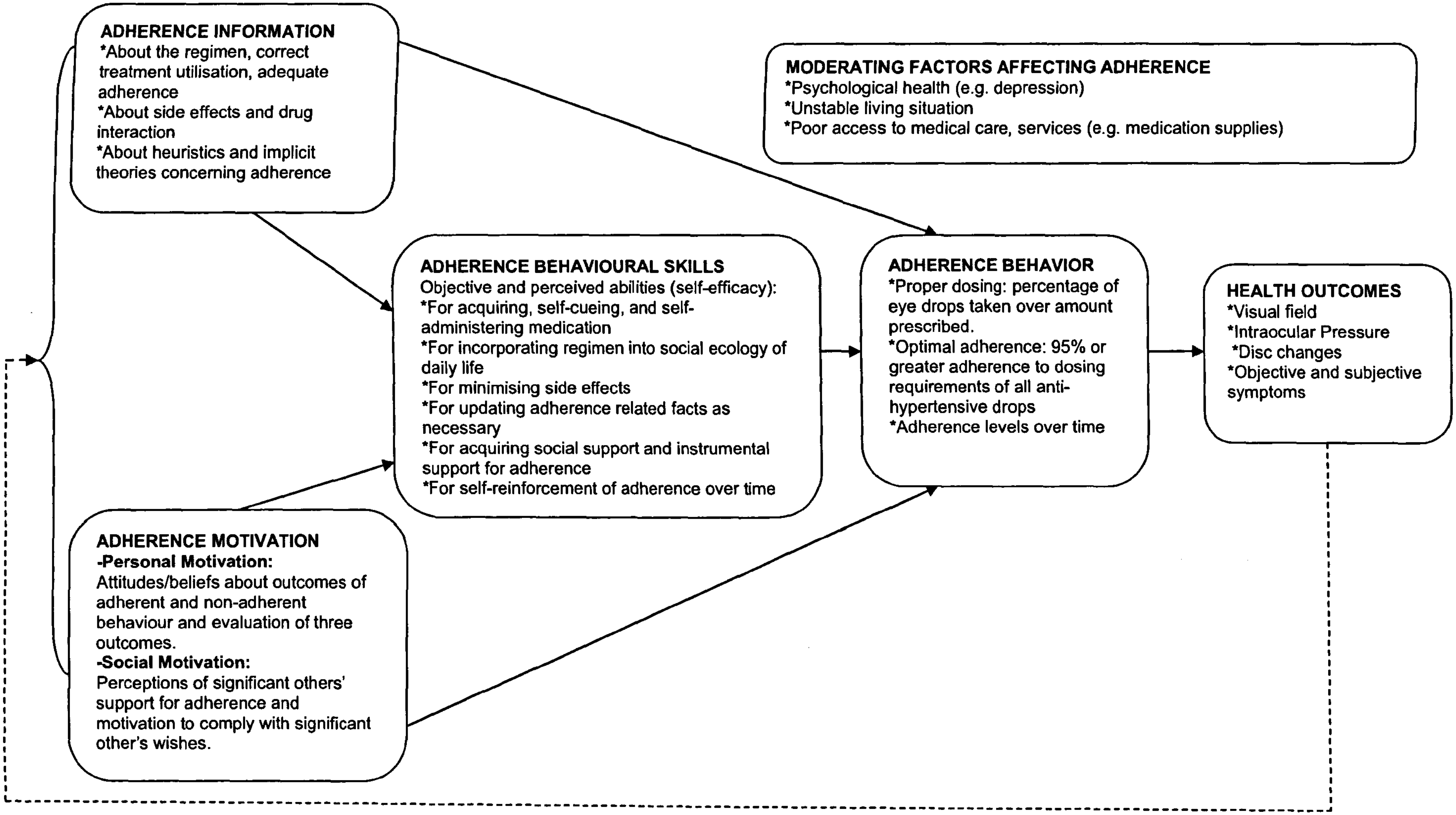


Figure (3.7): An information-motivation-behavioural skills model of therapy adherence (Adapted by Starace (2006) from the model developed by J. D. Fisher, et al, 2003).

3.5.3 Empirical Support of the IMB Model

Beyond its established strength in predicting, understanding, and intervening to change HIV risk behaviours, the IMB model is viewed as a generalisable approach to understanding and promoting health behaviours more broadly defined as examined earlier (Fisher and Fisher, 2000). In establishing the generalisability of this model, Fisher and Fisher conducted a review of the correlational research literature concerning socio-psychological factors linked to performance of diverse health behaviours. Fisher and Fisher (1999) found that in correlational research, information, motivation and behaviour skills elements are consistently related to health behaviour performance across diverse areas such as exercise behaviour, smoking cessation, breast cancer and cardiovascular health. In effect, there is considerable empirical support for the IMB model's fundamental assumptions that information, motivation and behavioural skills in the model are critical determinants of health behaviour change outside the domain of HIV prevention (de Vroome, et al., 1996).

A further review was conducted by Fisher, et al (2006) in which they examined interventions that contain information, motivation and behavioural skills elements. They observed that interventions that included the three elements were more effective in promoting health behaviour change than interventions that lacked one or more of these elements. When comparing the strength of the three elements contents of interventions that had strong health behaviour change effects, versus those with weak effects, they observed that the former had greater information, motivation and behavioural skills related content in comparison with the latter (Fisher and Fisher, 1996). Overall, the findings provide support for the IMB model elements as determinants of intervention efficacy across diverse domains of health behaviour change including disease preventive behaviour, disease screening and detection behaviour and behaviour related to adherence to medical treatment.

3.5.4 Critique of the IMB Model

The IMB model provides a comprehensive conceptual approach to understanding the determinants of health behaviour and may constitute a generalisable methodology for interventions that promote health behaviour change (Fisher and Fisher, 1999). This approach has been supported in elicitation, experimental intervention, and evaluation research conducted with diverse populations that showed significant sustainable positive changes. Results of such research are consistent with the IMB model's focus on identifying and addressing deficits in health behaviour relevant information, motivation and behavioural skills as an effective means for promoting health behaviour change. Fisher et al (1998) added that given the relatively recent birth of the IMB model, which was first published in 1992, it is not surprising that some areas of the IMB model-based research are somewhat sparse. Prospective studies of the determinants of health behaviour are fewer in number than cross-sectional and experimental intervention research, while much IMB model based research is still in process and not yet widely available.

A review in 2007 raised some questions about the role of the IMB model's information construct, which appeared to be inconsistent in predicting patient health behaviours and adherence behaviour (Munro et al, 2007). The model has specified situations where information itself is expected to be a substantial contributor to health behaviour and adherence behaviours; perhaps in relation to concordance issues could be raised. Further questions have been raised regarding the relationship between the information and motivation constructs that sometimes seems independent whilst others are dependent. Fisher et al (1994) argued that the IMB model's logic holds that well-informed people are not necessarily well motivated to practice healthy behaviour or adhere to their treatment regimens, and vice versa. This has implications for concordance.

3.5.5 The IMB Concordance Model

According to the IMB adherence model, provision of adherence support stresses the need to offer an individualized approach sensitive to patients' needs. Adherence is likely to be enhanced if the medical regimen fits patients' lifestyle and beliefs; they understood the regimen and if their concerns have been addressed. Fundamental to this process is the provider–patient communication dynamic that occurs within a clinical encounter that can be theorized using this 'concordance' model (Refer to Figure 3.8.), adapted from the IMB adherence model. According to this concordance model, for patients to be meaningfully engaged in their care, there is a requirement for them to have adequate information to participate as collaborative partners and to be supported in self-managing their condition. Practical steps for shared decision-making include outlining the range of options, providing information in their preferred format, checking understanding and exploring ideas to arrive at an agreed decision (Schneider et al, 2004). Of critical importance here is that it is an agreed decision between the patient and the healthcare practitioner.

The benefits of this collaborative concordance-based approach have been demonstrated in various settings, including improved adherence, increased patient satisfaction with care, reductions in the number of medications prescribed and in medication-related problems (Cox et al, 2004). Patient-centred communicative behaviours that stress a collaborative approach between doctor and patient have been shown to be associated with stronger coping mechanisms, improved quality of life, quicker recovery, and enhanced functional status (Silverman et al, 2006).

Despite these benefits, the extent to which concordance is routinely incorporated in clinical consultations is unclear. As noted previously, the term concordance is rarely used and early observations have shown low levels of concordance activity. Schneider et al (2004) identified barriers include patient reticence and doctors' lack of skills to facilitate the process. Given the complexity of self-management and concordance amongst glaucoma patients associated with factors like drug-related tolerability and effectiveness, the model presented an opportunity to understand concordance and guide the design of intervention.

3.6 Conclusion

This chapter has explored the concept of self-management in some detail and mapped policy responses in the UK. The current views and literature surrounding the EPP were also examined in relation to its effectiveness and cost-effectiveness. Theories of human health behaviour have been explicated with an emphasis on self-management and adherence. This chapter has concluded with a proposed framework for the research that is underpinned by the IMB model. Adherence and concordance have been shown as associations with the IMB model. Many of the issues discussed in this chapter will be revisited later in the Thesis and discussed in-depth in the Discussion Chapter. In the chapter that follows, the methodology employed in this research project is described. The IMB model is discussed in relation to how it has been applied in the EPP.

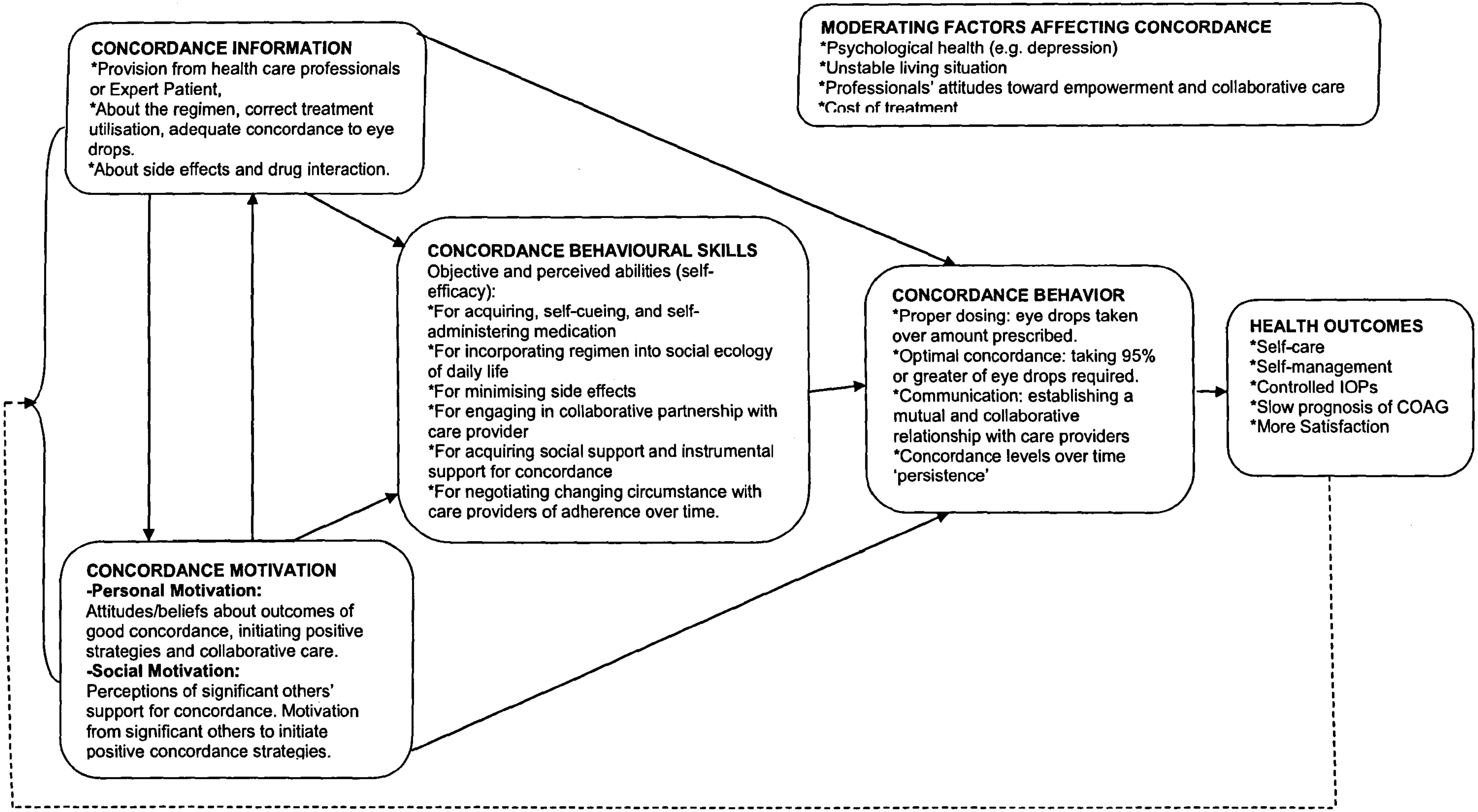


Figure (3.8): A modification of the IMB adherence model to demonstrate glaucoma concordance (Adapted from Starace (2006), from the model developed by J. D. Fisher et al, 2003)

Chapter Four
Method

4.0 Introduction

The methodology for the research will be presented in three parts. Part one will describe the use of an ethnographic approach to develop the GEPP. Part two will describe the use of a collaborative Action Research approach to implement the GEPP. Part three will describe the mixed method approach associated with the evaluation.

4.1 Methodological Account

As previously indicated in the introduction chapter, this research took place in three glaucoma outpatient clinics in Moorfields Eye Hospital NHS Foundation Trust. Two of the clinics were outreach clinics that serve the area of east London (Barking and Dagenham), which is an ethnically diverse community with high levels of poverty. The third outpatient clinic was based at the main hospital building at City Road and serves a less diverse community with lower levels of poverty.

In order to develop, implement and evaluate the intervention, the research team (The initial research team comprised a Consultant Ophthalmologist, the Nursing Research Lead in the Trust that is my City University London Supervisor, an Optometrist Research Fellow and myself) proposed the application of a mixed methodology (qualitative and quasi experimental quantitative design) comprising a before-and-after study involving action research. There was a strong belief held by the research team regarding the appropriateness of mixed methodology and the insight that potentially could be gained from engaging patients in designing and delivering the study through a collaborative approach. The Trust Research and Development Committee had a slightly different point of view where they preferred a large sample sized experimental study and a clear interest in supporting the undertaking of a Randomised Controlled Trial. It was evident to the research team that the data size required would be much larger than originally planned (approximately 1500 participants). The research team considered an RCT to be inappropriate. No preliminary research or pilot study had been undertaken and there was no evidence in the literature to support an RCT at this juncture. Therefore the team challenged the conduction of an RCT. Further meeting with the Research and Development Committee resulted in an initial 'stale mate' and then a compromise. It was agreed the team would undertake a feasibility exploratory study comprising a before-and-after design in preparation for an RCT. The team regarded this as appropriate prior to undertaking a larger scale RCT. Once a decision was made that a qualitative and quasi-experimental quantitative component would be undertaken (that would be followed by an RCT), the Research and Development Committee approved the research. It should be noted that this study is the first nursing research project to be undertaken in the Trust.

After data collection was initiated and following discussions with statisticians, the weakness of the before-and-after design in the absence of a control group was group in term of strengthening the validity when selected carefully, there was a risk of occurrence of contamination that could have serious effects on outcomes and reduce the apparent effect of the interventions. In addition, I was focused on the action research processes and the intervention that was being delivered by the Expert Patients. Therefore, on completion of the intervention phase of this research, great efforts were made to recruit a non-contemporaneous control group of participants to match the intervention group participants with respect to the key characteristics of the geographical area, setting, gender, age, ethnicity and number of participants. It must be noted here that the Research and Development Committee did not approve the inclusion of a control group in the research. The Consultant Ophthalmologist took it upon herself to fight for this addition to the action research project.

The Trust Medical Statistician calculated the sample size for each group. The Research and Development Committee agreed that for the purpose of this 'preliminary' study (it should be noted that would be followed by an RCT) that 5 Expert Patients and 25 clinic patient participants known as the 'intervention group' would be involved in the research. Following discussions with the Consultant Ophthalmologist the Research Development Committee agreed that an additional 25 patient participants (control group) could be included. This was deemed sufficient to discern the effect of the GEPP.

4.1.1 Participants and Participation

The development and implementation of the GEPP involved recruitment of three patient groups. First, an Expert Patient group who were experienced patients and received further training to deliver the intervention (The Ethnographic component of the research). Second, the patient participants group who were diagnosed with COAG within the last two years and were attending the clinic for their follow up care and received the intervention (The Action Research component of this research). The third group was a control group that did not receive any intervention other than the normal provision of information from the doctors and nurses but served the purpose of between groups comparison.

All patients included in this study were patients that attended the glaucoma clinics under the care of the Glaucoma Consultant Ophthalmologist that has been supervising this study in the Trust. As stated previously recruitment took place in three different outpatient sites in this Trust where the Consultant Ophthalmologist was running clinics. The Expert Patient group was chosen according to criteria described in Appendix (2) although the criteria received further adjustments to suit our patients. Five patients who met the suitability criteria and agreed to take part were asked to attend training workshops. The clinic patient participants were recruited on the day they visited the glaucoma clinic. All patients that attended the clinic that met the inclusion criteria were invited to take part. Those who agreed were recruited. An information sheet was distributed and participants given time and space to decide whether they wished to participate.

4.1.2 My Position as Researcher and Lead Investigator

The Special Trustees of Moorfields Eye Hospital NHS Foundation Trust and the International Glaucoma Association (IGA) in the United Kingdom funded my post as a researcher to conduct this study. My remit has been to improve the knowledge, experience and the adherence to treatment of recently diagnosed glaucoma patients attending the outpatient clinics. As noted previously, I came to this research with extensive experience having worked in the Accident and Emergency Department of the hospital as an Ophthalmic Nurse Practitioner. During this time I have worked with the health professionals who are involved in running the outpatient clinics and know them on a professional and personal level.

During my working career in the Trust I have worked with glaucoma patients in all stages of their illness attending Accident and Emergency for various reasons including: being referred for their primary assessment by Optometrists or General Practitioners, reactions to eye drops, deterioration of vision, and/or being diagnosed on their visit for a non-glaucoma related eye problem. Over time I became concerned about glaucoma patients poor knowledge and concordance to treatment, which was the primary reason for my involvement in this research. My concerns became so great that I initiated discussions with one of the leading glaucoma consultants in the Trust, who worked in the Accident and Emergency with me. This consultant shared similar concerns regarding adherence and concordance amongst glaucoma patients. We wanted to find ways to involve experienced patients in the running of the service. Having both shared common concerns and ideas about improving the patients experience and involving experienced patients in improving the experience of other recently diagnosed patients, this Consultant was very supportive, prepared and willing to facilitate this research.

In action research literature, there has been considerable debate about being an 'insider' as opposed to 'outsider' action researcher conducting a particular inquiry. As an 'insider' the investigator has a formal role in the study setting and is usually in paid employment, whereas an 'outsider' has no formal role in the setting other than in the action research itself (Waterman et al, 2001). I consider myself to be an insider from a staff point of view in the sense that I have known most of the people involved in running the outpatient clinics and 'being around' the clinics in either my clinical role or researcher role during the exploratory phase and the action phases of the research.

Writers have taken different views as to which model of researcher is more successful. Titchen and Binnie (1993) suggested that the 'insider' model they used in their research was the most successful. Meyer and Batehup (1997) having worked within the setting before called themselves 'insiders' although later on as management changed they felt like an 'outsider'. In a comparison, Waterman et al (2001) observed that 63% of outsider action researchers reviewed have been successful in achieving their aims as compared to 30% of insider action researchers. They also observed that both roles have their advantages and disadvantages as summarised in Table (4.1).

Table (4.1): Insider or outsider action researcher: Adapted from Waterman et al (2001).

Perceived positive aspects	Perceived negative aspects
Insider action researcher:	Familiarity clouded understanding
Improve understanding of context	Conflicting commitments causing delays
Enhance credibility with participants	Participants disclosed information reluctantly
Challenge barriers to change	Limited access to confidential information
Increase commitment to the study	Perceived as owning the data
Sustain change	Generating feelings of vulnerability
Outsider action researcher:	Difficulty in understanding context
Bring fresh perspective to issues	Time-consuming
Lead to empowerment of participants	Lack concern for long-term outcomes
	Have more to gain (e.g. higher degree).

Titchen and Binnie (1993) have advocated for what they called a 'double act' where one researcher was an outsider (researcher) and the second was an insider (change facilitator). Whatever stance taken, Ruth (2002) stressed that reflexivity and critical self-awareness are essential to help question biases from whether an individual is an insider or an outsider. In that sense I also considered myself as an 'outsider' having not worked in the glaucoma outpatient clinics before and being unfamiliar with the practices followed. Subsequently, I could bring a fresh perspective to examining issues. As an 'outsider' in the glaucoma clinics, it made me conscious that it is not easy for an 'outsider' to be present. I felt that some senior nurses involved in leading these clinics found my role threatening from the way they responded to my presence.

4.1.3 Steering Group

A steering group was established to monitor the research. The steering group was intended to include a patient representative right at the beginning of the planning phase of this study. However, due to the delay in gaining ethical approval for the study and as we were required to provide a detailed account of the plan of this research, it meant there was limited input from a patient's perspective at this stage. The original steering group comprised of The Nursing Research Lead at the Trust (City University London supervisor), Glaucoma Consultant Lead (second supervisor), Optometrist Research Fellow (Senior Lecturer in the Department of Optometry at City University London) and myself. The steering group oversaw the research in its initial phases of seeking access to the Trust outpatient clinics and the exploratory phase.

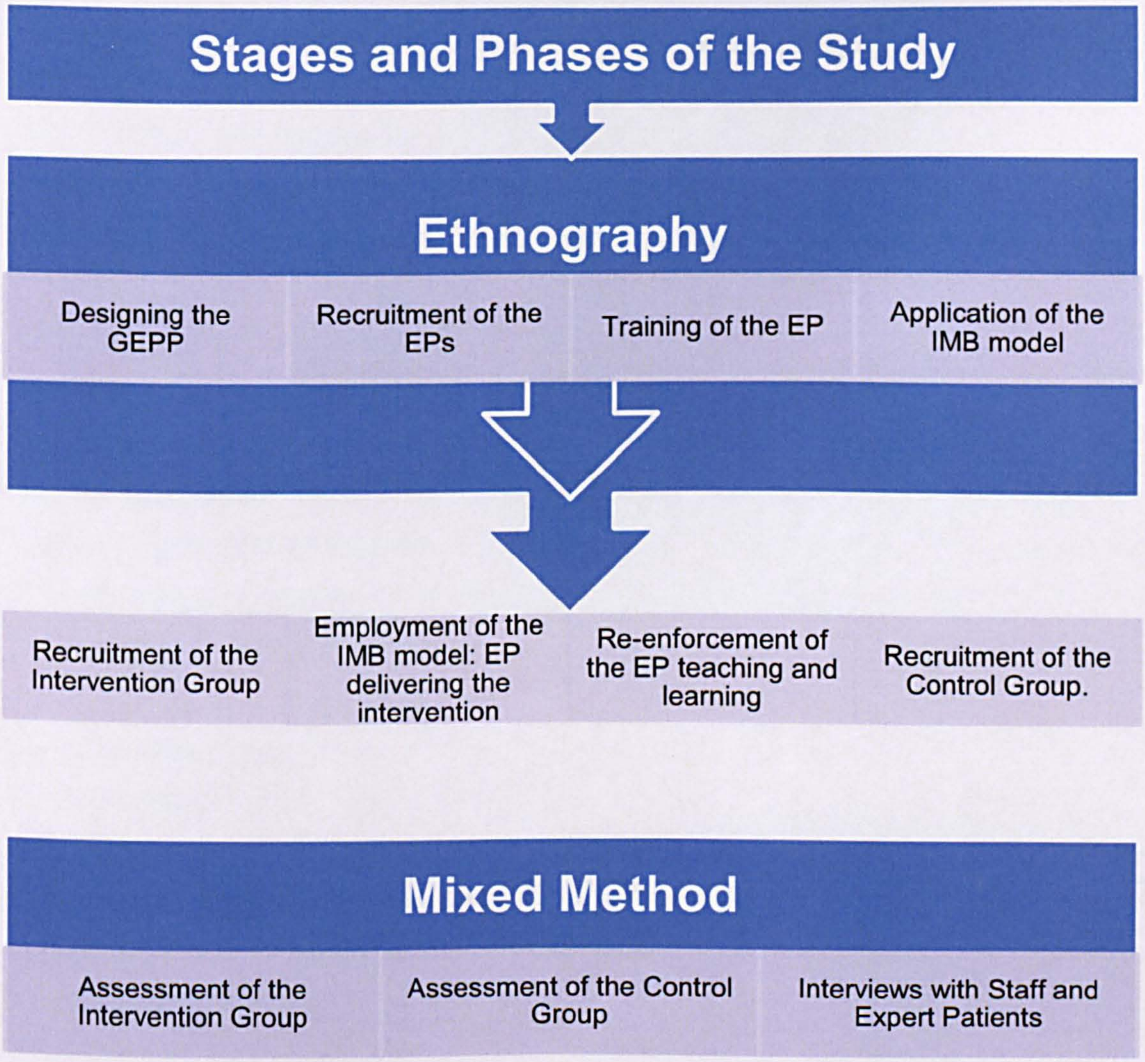
The role of this group has evolved and changed from one stage to another. In the early stages it played a primary role in seeking the approval of the Research and Development Committee at Moorfields Eye Hospital NHS Foundation Trust and getting the research through the strict scrutiny of the National Research Ethics Service (NRES). It has met regularly to obtain updates on issues like the study design, the tools to be used, the outcomes to be measured, Expert Patient recruitment and the content of the training programme for example.

Steering group members were experienced professionals and had been involved in different research projects in the past. As noted previously, there was no significant patient input at the early stages of this research; particularly in issues related to the Trust's Research and Development Committee approval and the subsequent NRES approval.

4.2 Stages of This Study

This study had three phases which are to an extent, connected with one leading to another. The following figure (4.1) presents a flow chart of the development of the different phases of this study from a methodological perspective.

Figure (4.1): Methodological Flow Chart



4.2.1 Exploration Phase (Ethnography)

This phase was an intense period of involvement for the various key players and lasted 6 months. During the ethnographic 'pre-innovation phase' (Meyer, 1993), I spent two shifts (8 hours each) a week in the first month to get to know the staff involved in running the glaucoma services closely and to conduct my observation tasks. In this phase, I made formal and informal presentations of the study proposed, emphasising the importance of its collaborative aspects. It was important to engage staff working in these clinics and encourage them to contribute, at an early stage, to building a picture and proposing possible solutions to the problem of adherence. I was surprised at the amount of trust that had already been built and the level of interest the staff showed in this research and how much they were prepared to participate in the study and be interviewed which was rather refreshing and encouraging at this stage; particularly in light of my feelings about how some senior nurses had regarded my presence initially. Concurrently, I was engaged in discussions and frequently met with the Research and Development Committee staff to seek permission for this study and to obtain the necessary ethical approval from the Moorfields Eye Hospital NHS Foundation Trust.

Data were generated in this phase to explore the nature of the problem and the focus of the study using different data sources consisting of reflective field notes based on my observation, gathering the views of the multidisciplinary team involved in running these clinics, views of patients attending the clinic and their comments on the service received. During the course of this phase, the research had input from other groups at different stages including patients, nurses, doctors, optometrists, researchers and outpatient leads. The following were involved at specific stages of this inquiry:

Ethnographic Phase
Expert Patients (n=5)
Nurses (n=5)
Outpatient Clinic Nurse Managers (n=2)
Doctors (n=3)
Research Lead (n=1)
Medical Statistician (n=1)

4.2.2 Implementation Phase (Action Research)

This phase started once the Expert Patients training had finished. This Thesis describes the use of a collaborative Action Research approach by presenting the different cycles involved in the implementation of the GEPP; starting with the recruitment of the Intervention Group and delivering the GEPP by the Expert Patients and similarly recruiting the Control Group. This phase will be discussed in detail in Part II of this chapter.

4.2.3 Evaluative Phase (Mixed Method)

This phase is an on-going phase that started at early stages of this study and continued throughout. Various data collection tools where used to evaluate the effectiveness of the GEPP including field notes, Expert Patient interviews and questionnaires, intervention and control group questionnaires and semi-structured interviews. Staff interviews will be discussed in detail in the last part of this chapter.

4.3 Part I: Ethnography

Part I is presented in this section and will explore the methodological decision made, along with an account of why ethnography was appropriate for developing the GEPP. This section commences with an account of the preparations and experiences that preceded the development of the GEPP and training programme, followed by implications and results from the meta-analysis conducted. The chapter concludes with a brief discussion component of the training programme (workshops) for the Expert Patients.

A closer look at the literature reveals that under the qualitative umbrella there are several approaches that share many characteristics but have distinct disciplinary and intellectual traditions and customs (Fetterman, 1998). Each approach is embedded within a research community and has its own criteria for judging trustworthiness and merit (Silverman, 2006). In this study three different methodological approaches were applied in three different stages. An ethnographical approach was used to explore the issues arising from designing and implementing the first part of the GEPP, whilst a collaborative Action Research approach was used when implementing part two of the intervention and part three explores the issues arising from its delivery. In the following section, the empirical support, rationale for using ethnography and its main characteristics are presented.

Ethnography fits well with action research because they both attempt to understand how a particular target group and a particular project work together (Alasuutari, 1995). Ethnography is an approach to research (LeCompte and Schensul, 1999). It is not one specific method (like participant observation, or interviews, or surveys). In fact, it is a multi-method approach. Moreover, ethnographic approaches integrate different methods into one holistic study (LeCompte and Schensul, 1999; Atkinson et al, 2001). I could not carry out and analyse a survey, for example, separately from interviews or in isolation from the diaries or field notes that I wrote. So I tried to look at all the knowledge and experiences together in relation to each other. Action Research links the research back to the aims and objectives of the study that will be discussed in the following chapter.

4.3.1 Rationale and Definitions

Describing this part of this study, as ethnography does not simply refer to the methods used for the research, which was participant-observation in three different settings, but also to the epistemological choices and the ethical commitments of the research. In contrast to the dominant biomedical model, it was important to consider how to explore knowledge associated with self-management of glaucoma and the lack of it at times. Ethnography, with its origins in the anthropological studies of `others' seemed an obvious choice for the study of patients with COAG. In particular, simple observation without being an active participant may not have been sufficient for exploring a situation where there is an obvious lack of knowledge and potentially 'hidden' dissatisfaction.

An ethnographic approach to exploring complex conditions (i.e. COAG concordance) provides rich understandings of the context and enables effective interpretations of knowledge and information (Atkinson and Hammersley, 1994). Ethnography literally means to "write a culture" and can be distinguished from other forms of qualitative research by its focus on culture (Walcott 1994). It is often defined as the learned social behaviour or way of life of a particular group of people (Fetterman, 1998) and traditionally based on long-term engagement in the field of study (i.e., Glaucoma outpatient clinics and its community.).

Culture informs what people think and do, which forms the lens through which I explored the experiences and the daily running of the outpatient clinics. Within a changing NHS, Edwards (2007:19) proposed that ethnography is an empirical method for studying "the experience of work at the point of production", where observation can generate important details and data. Geertz (1973) on the other hand, argued the value of ethnographic research in the exploration of health care cultures that contrast with the dominant biomedical model, are, to a large extent, that they are internally validated.

A key method is participant observation, where the ethnographer participates in the community and the setting being studied yet retains an analytical or observational position so that through reflection and analysis the ethnographer can describe and interpret the subject of the study (Wolcott, 1994). An ethnographer looks for patterns, describes local relationships, understandings and meanings which will help formulate and design a project based on the observed and felt needs of people (Hammersley, 1992). Throughout the study field notes based on my observations were kept. Details of my activities in the clinics have already been given, though other activities were also undertaken with the primary aim of collecting data. As the clinics were occasionally short staffed I was called upon to cover for their nursing staff shortage, so I wore my nursing uniform and had an active role attending to patients as part of the nursing team, which was an even better opportunity to bring me closer to my observation task. As a non-participant observer at times I was not content to observe and participate marginally in the everyday activities of running of the clinics, but instead sought to learn those activities by putting them into practice. The goal of this active participation (which is also recommended by Schwartz and Jacobs, 1979: 248–53) is not to become like the 'natives,' but rather to gain better understanding of their practices. Therefore my role in this phase varied from being a non-participant observer to a participant observer.

Some contemporary researchers share the early anthropologists' belief that in order to understand the world 'firsthand', the researcher must participate themselves rather than just observe people at distance. This has given rise to what is described as the method of participant observation. In a very general sense, Atkinson and Hammersley (1994:249) described *"all social research as a form of participant observation, because we cannot study the social world without being part of it. From this point of view, participant observation is not a particular research technique but a mode of being-in-the-world characteristic of researchers"*. I particularly enjoyed being a participant observer as it brought me closer to patients where their views were important for my data collection. As Silverman (2006) summed up, it also allowed me to pursue what people actually ‘do’, leaving what people say they ‘think’ and ‘feel’ to the skills of the media interviewer.

For example, I was attending to a 45 year old driver who was diagnosed with glaucoma two years ago and prescribed antihypertensive drops to be used until his next visit. He failed to attend the next few visits as he was travelling; eventually attended after two years of not using the prescribed drops. There was a progressive visual field loss and he could potentially lose his job as a result. I could not help but spend substantial time with him understanding what went wrong; which I would not be able to grasp if I was a mere observer.

Prior to immersing myself in the culture (the fieldwork), I identified individual ‘informants’ who were willing to interpret the outpatient culture from their perspective. These people were work colleagues and as this study unfolded became friends who gave me the support and confidence to complete this study. These informants were helpful in not only answering questions and queries I have raised, but they also brought to my attention certain issues which subsequently helped in formulating the final question and designing the GEPP.

The process of examining practices and behaviours of a group or community implies that ethnography is field-oriented and naturalistic (Fetterman, 1996). In an attempt to get immersed in the culture and balance insider and outsider perspectives, I remained in the clinics for a considerable amount of time, observing, interviewing and participating in health care provision.

This activity required taking an extensive amount of notes. Initially the amount of data was overwhelming and at times hard to make sense of. As a first time ethnographer I found myself bombarded with information and felt an urgent need to take notes all the time. Then my intuition started to play a greater role in deciding which data needed to be collected and when to document it and how. I know that it was important to maintain objectivity as a researcher and avoid *“going native”* (Burns and Grove, 1993). Data generated during this period has helped to uncover issues that were addressed in the GEPP and determined the direction of this study.

The notebook I kept with me was helpful in making an entry of my observation 'ideas and thoughts' as they occurred. I felt my notes could become relevant to the progress of the research with interpretations and reflections added. This varied from a comment made by a patient or an action taken by one of the nursing staff involved or even a telephone conversation with a patient. Often there was limited time to make a full entry. Occasionally I wrote a phrase or a word so that my memory would be triggered when more time was available to make a full entry. My one-hour commute train trip home was always handy in summing my day and going through my field notes that were written up the same day.

Patients' views were recorded differently. Initially I asked patients questions about their thoughts of the consultation and the care they received. Their answers were insightful in assessing how satisfied or dissatisfied they were and what they valued and remembered most, but it left me with copious amounts of field notes which were not necessarily helpful in observing what actually went on in the consultation. Additionally, it was almost impossible to compare the field notes from one patient to another as their responses were quite varied. As I was going through my field notes I felt:

> *"Very frustrated and uncertain about what I should be asking and recording, As my field notes are piling up on my desk I know I am doing something wrong. There has to be another way of doing this"*
>
> "Reflective Diary"

As I became more confident in recording patients' views, I developed a list of closed-ended questions to be asked of all newly diagnosed patients that had either a yes or no answer (refer to appendix 1). In this way I could avoid collecting a large amount of field notes that did not allow comparisons or draw any conclusions. Patients were asked whether they were given information about the diagnosis, medication use and future visits and any further comment they would like to make. These notes allowed views of the patients and their levels of knowledge to be captured and recorded to inform future decisions regarding the content of what would be an Expert Patient training programme. In this phase, field note entries were recorded covering the following activities:

- Observation of the MDT including Ophthalmologist, Optometrist, Nurses and Clerical staff.

- Records of meetings with patient participants.
- Records of information meetings with participants.

4.3.2 Research and Ethnography Aims

As mentioned earlier the overall research question for this research can be formulated as follows: "Does the development and implementation of a GEPP improve knowledge and concordance amongst newly diagnosed glaucoma patients?"

The aim of the explorative phase 'ethnography' is to take a holistic approach to the subject being studied and to look at the whole social setting and relationships and subsequently try to contextualise these in wider contexts (Bryman, 2001). The purpose of the ethnographic part therefore, was to explore the complete range of patient-professional interactions and the processes involved in service provision at the glaucoma service, including:

- The immediate circle of health professionals and the team involved in running the service, how they are organised, how they carry out their work, how the project fits into their daily activities;
- Patients, their everyday lives with this condition and ways of doing things, interaction and communication with health professionals, their views on service provided, expectations and satisfaction;
- The wider social context (e.g., social divisions and socioeconomical variations related to the condition and the service received and language issues),
- Social and environmental structures and processes beyond the patients and to some extent the health professionals running the service.

4.4 Participatory Observation in Detail

My fieldwork role as an ethnographer was a process of 'observation through participation'. This has ranged from being a complete observer to complete participant depending on the situation I was experiencing. As an observer many insights were gained from listening to consultations with professionals and feedback from patients, interactions with patients' relatives and carers, listening to telephone conversations, observing relationships between professionals and listening to personal tales and experiences.

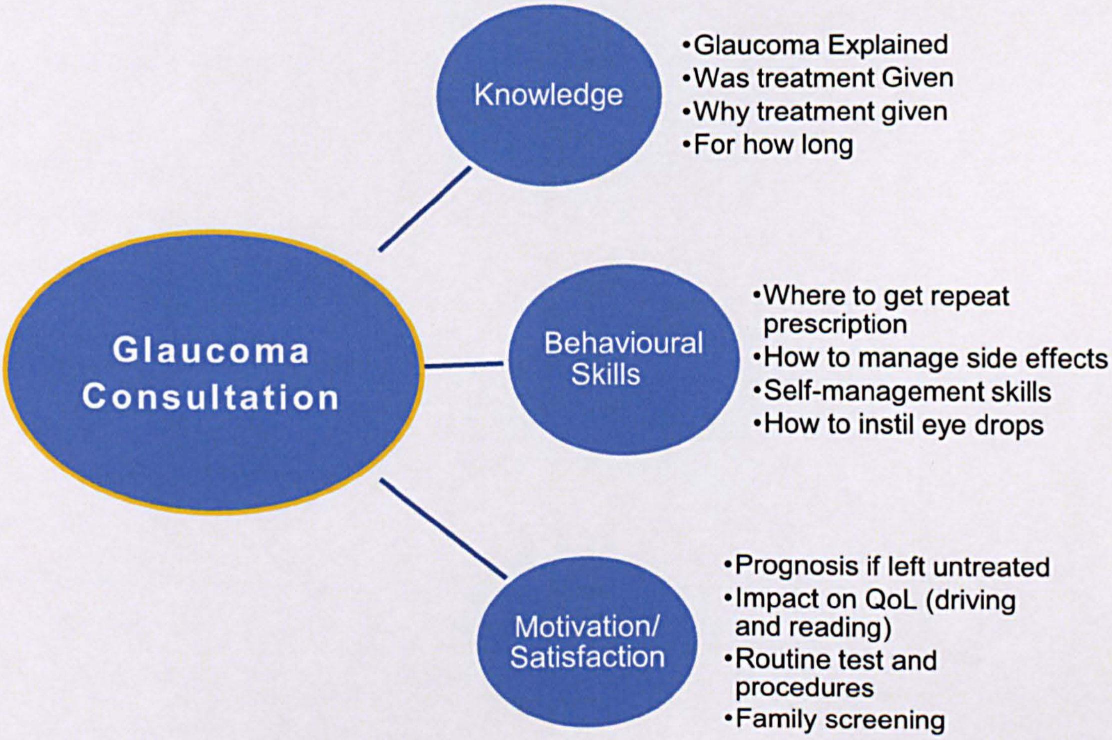
For this intervention to complement the care provided in the outpatient clinic, it was essential to understand and examine the health care provided for patients attending the clinic. It was also critical for the success of this research to build rapport with the staff running the clinics and to understand my role in this research and what exactly I was trying to achieve. Having worked in the Trust for seven years and having a good working relationship running the service has allowed me to closely observe the running of the clinics over four weeks. As data were generated it became clear that there was inconsistency in the care provided. On an ordinary day, as the clinics were getting busier and waiting times getting longer, patient encounters with professionals tended to become brief and to focus mainly on basic questions, i.e., what eye drops are you taking? Do you have any allergy or medical condition? Any problems with eye drops?. To overcome this inconsistency, it was essential to get a sense of the scope of the problem as the data generated became messy and hard to comprehend. Therefore, I designed a checklist of questions (Table 4.2) that presumably covered what was discussed in consultations with the professionals. It comprised the following:

Table (4.2): Observation Checklist.

GLAUCOMA What is glaucoma? Was the condition explained to you?	Yes ☐	No ☐
Was treatment given?	Yes ☐	No ☐
Why they were given?	Yes ☐	No ☐
For how long to be used?	Yes ☐	No ☐
Where to get a repeat prescription if needed?	Yes ☐	No ☐
Self-management and self-care?	Yes ☐	No ☐
FUTURE VISITS: Prognosis of glaucoma if untreated?	Yes ☐	No ☐
Tests and procedures to be carried out on future visit?	Yes ☐	No ☐
OTHER ISSUES: Family screening?	Yes ☐	No ☐
Driving?	Yes ☐	No ☐

Thirty patients were asked the above questions as they were leaving the clinics to establish an idea of the quality of the consultation they received. The aim of this exercise was to identify issues that needed to be addressed in the intervention. The data extracted from this checklist were analysed based on the IMB model as follows in figure (4.2):

Figure (4.2): Observation data analysis based on the IMB model.



To reveal the cultural knowledge entrenched in the outpatient clinics a number of enquiry techniques were utilised. As mentioned earlier, ethnography entails the use of various techniques to capture rich and deep insight (Fatterman, 1998). In addition to observation, interviewing was another technique used frequently throughout this ethnography. It ranged from the form of spontaneous, informal conversation, to more formally arranged, in-depth interviews and short surveys.

For instance, the health professional interviews were primarily in the form of informal conversation. For most it was a welcomed opportunity to talk about their own experience and difficulties they were facing running the clinics and the changing culture of the NHS. To an extent they indicated they were not only speaking to a researcher conducting a study, they were also sharing it with one of their colleagues to whom they could relate.

4.5 Planning the GEPP

This phase actually started at the beginning of this research. However, it continued throughout the study. At times I had difficulty in separating the ethnography from the action research. It was during this early stage that a number of action research cycles began to emerge as spirals of activity that led to the development of the innovation and preparation for implementation of change. Each cycle was planned to comprise a period of planning, acting, observing, reflecting and re-planning with the primary aim of involving participating patients and staff through a variety of actions to initiate the GEPP. Although this sounds like a one-dimensional activity, the reality was far more complicated and at times confusing.

Data collected in the exploratory ethnographic phase identified that staff involved in the outpatient clinics recognised that the care provided was patchy and fragmented. Live examples from my observation also raised questions about how informed glaucoma patients attending the clinics were about their conditions and treatments prescribed. The poor level of knowledge and adherence amongst clinic attendants that has emerged from this research has confirmed this and will be discussed later. Although this could be partially contributed to difficulty in retaining information by newly diagnosed patients, despite being given sufficient information, the benefits of the EPP are therefore, to provide additional opportunities for reinforcement of key information.

Raising the profile of the GEPP was initiated and included undertaking local, regional and national presentations on how the GEPP was developing as well as presentations in tutorials running in the Trust on a weekly basis. Further consultations with professionals involved in self-management programmes and patient support groups that involve recruiting and training volunteers were undertaken. An example is Dr. Alan Simpson and his extensive work with patients with mental illness which involved training and supporting them to gain more control over their lives and resume and lead a more independent and productive life. Governmental organisations and charities involved in similar work were consulted, for example, the International Glaucoma Association (IGA) was instrumental in their input and support in shaping the content of the Expert Patient training programme. Key internal stakeholders views on how the training and the intervention should be developed were sought. More importantly, potential Expert Patients were very insightful and encouraging as they shed light on their own valuable experiences with glaucoma when asked what they would have wished to happen when they were diagnosed.

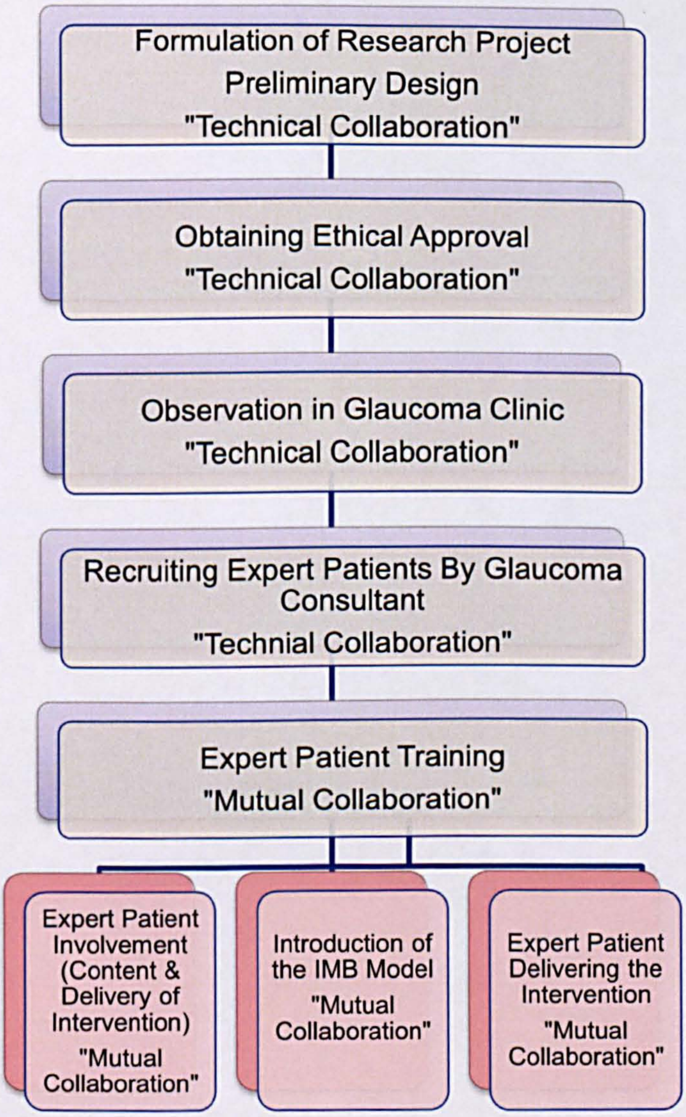
The Steering Group, overseeing the design and implementation of the GEPP, was also involved in discussions with the Moorfields Eye Hospital Research and Development Committee on the design of the study, sample and outcomes to be measured. The drive behind establishing this group was to resolve difficulties encountered by the Research and Development Committee and subsequent ethical approval as well as overseeing the research as a whole.

4.6 Development of the GEPP

In designing the training programme many considerations were taken into account. First, based on the results of the meta-analysis and lessons learned from Kate Lorig et al's research and subsequently the recommendations of the Department of Health EPP the skeleton of the programme was built. The 'felt needs' as expressed by the Expert Patients and other fellow patients interviewed during the exploratory phase added a patient perspective to the programme. 'Felt needs' are needs perceived by patients who have COAG that have been expressed in their own words during interviews regarding things they thought were important to them but were not addressed during their consultations in the clinic.

This is a fact that I was keen to illustrate, right at the beginning of this research. My intention was to put patients' needs and their participation at the heart of this inquiry even though their input was limited at earlier stages in the research when the process of gaining ethical approval was initiated. Additionally, bearing in mind the uniqueness of COAG, suggestions made by professionals involved were taken into account as to the type and amount of information to provide the Expert Patients without overwhelming them with the task they were about to undertake.

Figure (4.3): Flow Diagram of the GEPP (blue represents ethnography and red represents AR)



As illustrated in the flow diagram (Figure 4.3), this work began with formulating the research and writing the proposal for the purpose of obtaining ethical approval. Then it went through an observation period "ethnography" to understand the practices of the glaucoma clinics. In trying to understand the current situations and practices and improve them, many questions needed to be answered and further ones to be formulated. Therefore, the study took a new methodological approach. A collaborative action research process was employed in this part of the research, as the research proceeded through a spiral of planning, action taking, data collection, analysis and critical reflection. These activities reflect the collaborative nature of this research that is explicated further on in this chapter.

4.6.1 Meta-analysis: Lessons Learned

In preparation for the research and with a lack of glaucoma specific self-management programmes in place, a meta-analysis was conducted in an attempt to examine successful examples of self-management programmes for different chronic conditions including arthritis, diabetes mellitus, heart disease and hypertension. An example of these programmes is the Department of Health generic "Expert Patient Programme". This phase began by undertaking a literature review of self-management programmes designed and delivered by Expert Patients to chronically ill patients with a view to applying them in an ophthalmic context as discussed in the previous chapter. The result of the meta-analysis was consistent with available evidence and literature that Chronic Disease Self-Management Programmes are effective in improving patient health outcomes for chronic diseases such as arthritis, hypertension and diabetes. The findings from the meta-analysis also demonstrated improvement in some indices including health status, health outcomes and increased symptom control but were not statistically significant. These improvements occurred within the first six to eight months and were not monitored thereafter. Based on this meta-analysis there were no definite answers to the shape and content of the GEPP. However, there were plenty of lessons learned from Kate Lorig et al's (1999) CDSM model and the self-management training programme they developed. The following are elements associated with successful programmes that can be incorporated into the GEPP.

4.6.1.1 Follow up

The majority of studies conducted in this context have followed their subjects over a time series (baseline, one to three months and six months). Though some experimental studies went beyond six months and followed patients up to 1 year. It was deemed sufficient in most studies to follow up to six months to ensure that such an intervention is sustainable. In this study, in addition to the questionnaire used to evaluate participants' responses, semi-structured interviews were conducted to obtain a deeper insight into the patient experience with the GEPP.

4.6.1.2 Mode of Delivery

An intervention mode of delivery has varied amongst studies. Some studies have trained health professionals running the service to deliver the intervention, while the majority sought a more participatory and empowering approach to train volunteers to deliver the intervention. Programmes that have used the principles of empowerment, participation and adult learning have been proved to be the most effective. In my study it was essential to get participants involved in this enquiry. Recruiting and training volunteers, though more difficult and time consuming, has added a patient perspective; something often overlooked when conducting such an inquiry.

4.6.1.3 Outcomes Measured

The primary and secondary outcomes measured in the majority of self-management programmes have been generic in nature. They measure the impact of these programmes for patients with varied chronic conditions. Outcomes measured include:

- **Health Behaviours (Self Efficacy)**

Stretching and strengthening exercises, aerobic exercise, and cognitive symptom management.

- **Health Status**

Self-rated health, disability, dietary habits, pain/physical discomfort, psychological well-being, energy/fatigue, and health distress.

- **Health Service Utilisation**

Medical doctors and Accident and Emergency Department visits, number of hospital stays and days in hospital.

These measures, though relevant, would not reflect the impact of the glaucoma intervention envisaged for the present research. It was recognised that as with medication, one therapy or programme might not be suitable for all patients. This is a fact that shifted the argument to weather disease-specific programmes are more desirable to address the unique issues that face patients with chronic eye conditions like glaucoma. Subsequently, several meetings were held with my supervisors to decide how best to choose outcomes that when measured are sensitive to and able to reflect the impact of the intervention. Of which, level of knowledge, motivation/satisfaction and behavioural skills essential for concordance were chosen as outcomes measures based on the IMB model constructs.

4.6.1.4 Setting

Based on the meta-analysis, there was no evidence to suggest which setting is more effective to deliver the self-management programme; however, for self-management interventions to have greater uptake, thought should be given to how and when they are offered to patients. My view was that introduction and endorsement of these programmes at a clinic visit will probably ensure higher rates of participation. Therefore, it was agreed that this intervention would be delivered at the hospital outpatient setting to complement the care provided by professionals and fill the gaps where professionals failed. This required a good understanding of the current practices and the running of the clinics to ensure smooth delivery of the intervention.

4.6.2 Uncovering an Alternative Theoretical Perspective

As discussed earlier (refer to Chapter Three), reviews of interventions that target adherence and concordance amongst glaucoma patients indicate that with very few exceptions, interventions have not been based on well-articulated and well-tested behaviour change theory (Olthoff et al, 2005) and further have not demonstrated a significant impact on patients' adherence behaviour. Some of the interventions that have been reported to be effective have had significant methodological shortcomings. They have demonstrated positive effects only within a relatively brief time frame after intervention and may have critical limitations associated with self-selection of participants, use of select and not necessarily representative teachers, limited generalizability of effects, and limited potential for widespread application.

Interventions reviewed in the meta-analysis fell into two main areas; self-efficacy theory, or an educational model expanded to incorporate other components such as social support, exercise and other skills. Glaucoma, unlike the other conditions reviewed in this Thesis, is asymptomatic in nature and therefore has one of the poorest rates of concordance in comparison with other chronic conditions. A review of research has indicated that interventions of an educational nature have been particularly successful in improving concordance levels amongst glaucoma patients (Olthoff et al, 2005).

It was necessary to discern a theoretical model that explains and addresses the issue of concordance in depth. With the similarity (asymptomatic and non-apparent need for treatment) between the concordance of HIV/AIDS sufferers and glaucoma patients' concordance, the IMB model was selected as the framework that the ethnographic component has been founded.

The present research applied the Information-Motivation-Behavioural Skills (IMB) model (Fisher and Fisher, 1992, 2000) (described in chapter three) which is a well-established conceptualization for modifying behaviour with demonstrated intervention efficacy (e.g., Fisher et al, 1994; Carey et al., 1997; and Fisher and Fisher, 2000), to design, implement, and evaluate the GEPP.

According to the IMB model, glaucoma concordance information, motivation, and behavioural skills are the fundamental determinants of positive health outcomes and preventive behaviour. Information that is directly relevant to glaucoma self-management and concordance and easy to apply in an individual's social setting is an initial prerequisite of successful self-management programmes. Motivation to engage positive self-management behaviour, including personal motivation (favourable attitudes toward awareness and adherence) and social motivation (perceived social support for these attitudes), is a second prerequisite and determines whether well-informed individuals will be inclined to act on what they know concerning glaucoma self-management and adherence. Behavioural skills necessary for performing self-management specific acts and a sense of self-efficacy for doing so, are a third critical prerequisite and determine whether even well-informed and well-motivated individuals will be capable of enacting glaucoma concordance behaviours effectively. According to the IMB model, to the extent that individuals are well informed, highly motivated, and skilled, they are expected to initiate and maintain strong self-management patterns of glaucoma adherent behaviour.

4.6.3 Development of Expert Patients Training Programme

It was apparent at this stage that the intervention with the Expert Patient must be a proactive educational programme with additional practical skills that would enable the glaucoma patients' participants to assume greater responsibilities and play a central part in managing their condition. This fitted very well with the principle of the IMB model which considers knowledge, behavioural skills and motivation as the main prerequisites and constructs of improving concordance amongst patients with chronic conditions like COAG. However, each one of these constructs is not enough in isolation to achieve self-management.

The GEPP and more specifically the training programme for the Expert Patients consisted of interactive activities that were designed to address each one of the IMB constructs (refer to Figure 4.4) including glaucoma information, motivation and concordance, and behavioural skills.

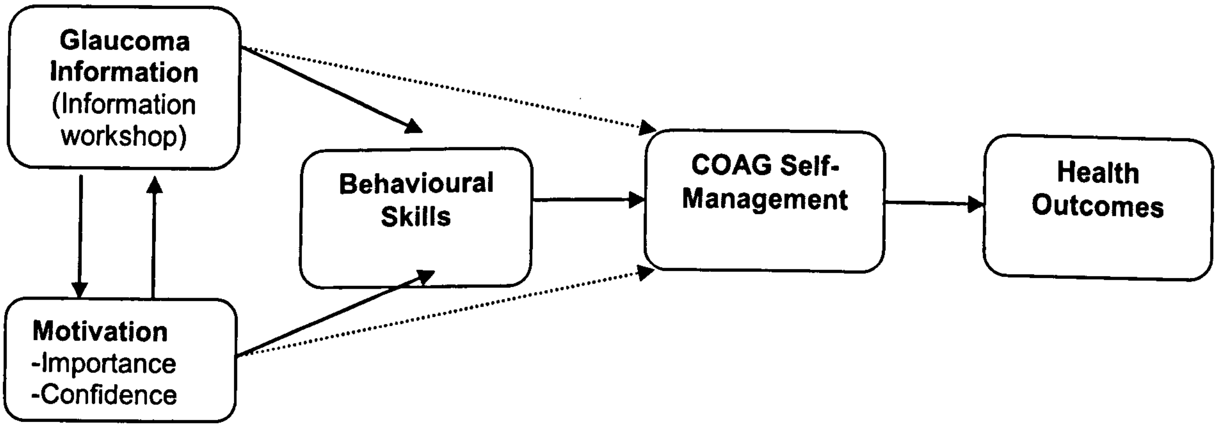


Figure (4.4): Contribution of information, motivation, and behavioural skills to COAG self-management and health outcomes: Adapted from Fisher et al (2003).

4.6.4 Expert Patient Recruitment

Patients with established COAG attending glaucoma clinics at Moorfields Eye Hospital NHS Foundation Trust were invited to assess their knowledge, compliance and satisfaction with the treatment they received as well as assessing their suitability to become an Expert Patient using an adapted criteria developed by the DoH (refer to Appendix 2). All efforts were made to ensure the representation of the chosen sample to the targeted population attending the clinic. Patients identified as having good knowledge and vast experience with COAG and capable of delivering the intervention, were invited to take part in the training programme designed, based on the IMB model, to particularly boost their preparedness and findings of this phase were fed into this cycle of the action research.

Five Expert Patients were recruited and given the recruitment package and time (up to one month) to carefully read and consider the information provided. Upon their agreement to participate in the research, a signed informed consent form was obtained from each Expert Patient. At this stage a demographic instrument was completed as well as identification of dates to attend a training programme that was provided by the research team.

- *Inclusion criteria for the Expert Patient*

Patients who have been using the service over the last 10 years or more were eligible to take part in the study as an Expert Patient provided they:

a) Had COAG for more than 10 years;
b) Were aged 25 years or more;
c) Were able to complete a questionnaire and comply with instructions;
d) Agreed to participate in the research by signing the consent form.

- *Exclusion criteria:*

a) Under the age of 25 years;
b) Had COAG for less than 10 years;
c) Difficulty understanding or communicating in the English language;
d) Unable to fully understand and comprehend the consent form.

4.7 Delivering the GEPP to the Expert Patients by the Research Team

The GEPP is a group educational programme designed to inform, motivate, and improve skills of people living with COAG who wish to become better self-managers "Expert Patients". A training programme was provided to orientate the Expert Patients to the learning and teaching strategies required for interacting with patients. The programme was highly interactive with very little passive learning. It incorporated the following topics:

- Discussing questionnaires;
- Expert patients and self-management in the NHS;
- Glaucoma: developing further understanding of the condition;
- Behavioural skills: guidelines in instilling eye drops;

- Motivation, confidence and concordance;
- Health coaching: coaching relationship stage by stage;
- Coaching and learning strategies;
- Motivational interviewing;
- Scenarios and role-play.

Specific discussions were held with the Nursing Research Lead at Moorfields Eye Hospital NHS Foundation Trust and Lead Glaucoma Consultant to decide on the role of each one of us would take in delivering the training and other logistic details. The main focus of this training was providing the training in an array of COAG self-management areas while maintaining a core focus on using anti-hypertensive eye drops as well as enhancing patients' understanding of their condition. As the research unfolded and Expert Patients became involved, the Glaucoma Specific Self-management Programme (GEPP) was developed.

4.7.1 Discussing Questionnaires

Although Expert Patients showed a considerable understanding of their condition, it was essential to explore this understanding and build on the Expert Patient strengths to boost their confidence. The Expert Patients were asked to complete the questionnaire intended to be completed by Clinic Patient Participants to assess their own level of knowledge and satisfaction in glaucoma management. The reason was to ensure all participants were familiar with the questions and appropriate answers.

4.7.2 Expert Patient and Self-management in the NHS

An Expert Patient is a patient who is an expert in his or her own right in the skills of how to cope with COAG. Expert Patients have comprehensive knowledge of their condition, confidence and experience in working in partnership with health professionals.

Although there was some degree of consensus regarding Expert Patients' increasing power, some authors believed that this modification did not imply de-professionalization of physicians, or censuring of the dominant biomedical knowledge (Fox et al, 2005). According to these authors, greater knowledge among patients regarding their state of health or disease did not directly imply loss of physicians' authority nor conforming to the medical model by being 'good' or doing the 'right thing'. In fact the EPP is likely to bridge this gap and help in the reformulation of the patient-physician relationship. In other words, the value of the Expert Patients is not in being a surrogate for ensuring compliance with the medical model or counter posing the decision-making powers of physicians, but in empowering newly diagnosed glaucoma patients to feel in control of their destiny and acknowledging their choices.

4.7.3 Glaucoma: Developing Further Understanding of the Condition

An interactive group workshop was designed by my supervisor and myself to provide information about different areas related to glaucoma, such as what glaucoma is, the prevalence of glaucoma, how the eye works, different types of glaucoma, the treatment available, and other related information. To manage their condition, COAG patients need basic information about glaucoma, prognosis, treatment, and the risks associated with poor concordance. Knowledge goes beyond basic information giving. Patients need to understand their personal ophthalmic history, knowledge of their eye drops and frequency, when and where to seek help when needed and to be encouraged to ask questions, and compare results of Intra Ocular Pressures and Visual Fields each visit. In the training programme the Expert Patients learned how to assist participants complete questionnaires and identify areas where knowledge was lacking. A well-validated 29 true-false items instrument was used to assess the Expert Patients' knowledge of glaucoma (Hoevenaars et al, 2006) (refer to Appendix 3). It assessed issues including eye drops use, intraocular pressure reading, visual field loss, and other related information. This questionnaire was also used to assess the Intervention and Control Groups participants' level of knowledge. This was followed by assessment of motivation and adherence.

The Glaucoma Ophthalmologist Consultant explained basic anatomy and physiology of the eye so as to familiarise participants with the terminology used in glaucoma health care. Routine eye examinations in the glaucoma clinic as well as therapeutic procedures including laser treatment and surgeries were explained. Visual aids were used to demonstrate deteriorations that occur as a result of glaucoma.

4.7.4 Behavioural Skills: Guidelines in Instilling Eye Drops

Behavioural skills that are essential to promote good understanding and ensure safe administration of eye drops were assessed. The Expert Patients were asked how they administer their eye drops; then provided with the appropriate technique to instil eye drops and use aids when necessary. The IMB framework provides another dimension in assessing patients' confidence in their abilities to change perceptions and concordance toward glaucoma, and the importance of doing so. For instance, a patient who underestimates the risk of poor concordance and the potential loss of sight is likely not to follow the treatment regimen in spite of being knowledgeable. As COAG is common amongst elderly patients with noticeable difficulties in dropping eye medications, further arrangements have to be made to ensure safe and effective administration, i.e. involving a family member in the care of the patient if appropriate or to notify the team if the patient continues facing difficulties in dropping their eye drops.

4.7.5 Motivation and Adherence

Motivation is a fundamental determinant of concordance and adherence to treatment regimens and readiness to change behaviour. It reflects two main components: importance and confidence. On the one hand, patients may be confident that they are able to manage their treatment and take eye drops consistently, but they cannot see the point of doing so. On the other hand, patients may be aware of the need to take their eye drops, but lack the confidence in doing so. In both cases patients will have poor concordance but for two different reasons that should be addressed accordingly. In this case ensuring that patients possess the necessary behavioural skills is essential.

Anti-hypertensive drops adherence and motivation were assessed with two multi-item scales. Eye drops adherence was measured with a self-reported form listing the number of times patients forgot to use their eye drops in the last four weeks. Each Expert Patient was asked to use a scale of 1(once) to >10 (more than ten times) to assess their adherence (refer to Appendix 4). For the other multi-item scale they were asked to assess their level of satisfaction with the treatment regimen and eye drops use including the effectiveness of the treatment, ease of administration, side effects, eye appearance on a scale 1 (extremely satisfied) to 5 (extremely dissatisfied) (Day et al, 2006) (refer to Appendix 5). The point of asking the Expert Patients to complete these questionnaires was to familiarise themselves with the questions and the choices to choose from. The same tools were used to assess each group at the conclusion of this study (refer to part III). Finally behavioural skills were addressed.

4.7.6 Health Coaching: Coaching Relationship Stage by Stage

A health coaching model (Berry, 2007; Abraham and Gardner, 2009) was employed that provides principles, techniques and guidance so that Expert Patients knew which techniques to use with a patient at any point during the intervention being taught. These techniques take into account the patient's learning readiness, perceived importance and confidence in making recommended behaviour changes. Expert Patients were taught how to form a partnership with fellow patients in the clinic where patients define their own goals, and identify what is needed to bridge the gap between where they are now and where they want to be. Planning a strategy that is flexible and gives fellow patients a framework in which they can identify steps and stages to work on to achieve their main goal were discussed. Expert Patients were trained to help fellow patients break their main goal into smaller manageable goals with a daily actions list that they can perform consistently to achieve their goal. The process involves:

- Knowledge;
- Empowerment;
- Action Plans;
- Monitoring and reviewing.

4.7.6.1 Knowledge

This is the first stage of coaching in which the Expert Patient assesses the level of knowledge participants have and covers information that patients lack. Patients have to understand the risk factors, targets, treatments and side effects available for their condition to be able to set their own daily actions. The aforementioned was incorporated into the Expert Patients training.

4.7.6.2 Empowerment

Expert Patients were taught how to persuade fellow patients to engage with health professionals collaboratively and ask questions that are important to enable patients to understand their condition and play an active role in the service and care they receive. For example, the Expert Patients were taught to encourage patients to ask questions about their visual acuities, Intra-Ocular Pressure readings and/or visual field performance. The Expert Patients were taught how to encourage patients to report any side effects of drops and discuss altering their doses if appropriate or consider changing their drops.

4.7.6.3 Action Plans

The Expert Patients were taught how to negotiate a developmental plan with fellow patients that describes the target goals in simple but SMART (specific, measurable, achievable, realistic and time-based) terms. In this activity the patient is supported in considering options and how to work out a plan to achieve their goals.

4.7.6.4 Monitoring and Reviewing

When reviewing coaching progress, I considered not only progress in relation to patient development and goals, but also the quality of the relationship and the process that enabled this to happen. Expert Patients were taught that the monitoring stage is a continuous stage throughout the course of action and starts at the end of each session, at a designated point within the period of the relationship and at the end of the relationship with the fellow patients. Expert Patients were taught they should discuss briefly with the patients how they felt the session went and whether it met their expectations.

4.7.6.5 Scenarios and Role Play

Since it was unlikely that examples of self-management would be in place, scenarios were created (refer to Appendix 6) in which different self-management skills (e.g., understanding their condition, instilling their drops and complying with their treatment, physiological and activity monitoring and care-related information) would become embedded in the patient's care structures.

The scenarios were based on 'felt needs' as expressed by Expert Patients and role play by the Expert Patients themselves whilst allowing other Expert Patients and the research team to provide feedback. The scenarios were built around sensitive issues that professionals face in their daily care of patients. For example, compliance with eye drops, terminology, driving vehicles, glaucoma, side effects of eye drops, and instilling the eye drops were considered. Interactive feedback techniques were used to allow participants to draw on their own experience whilst allowing other participants to feedback. The following is an example of the scenarios used in the training:

Scenario 1: Compliance
Patient:
A 58-year-old taxi driver was diagnosed with glaucoma 3 months ago. He was prescribed a beta-blocker to be applied topically twice a day. On the next visit his wife says he is not taking the medications regularly. The patient does not think it is important to do so and thinks it is enough to do it once a day or just twice a week.

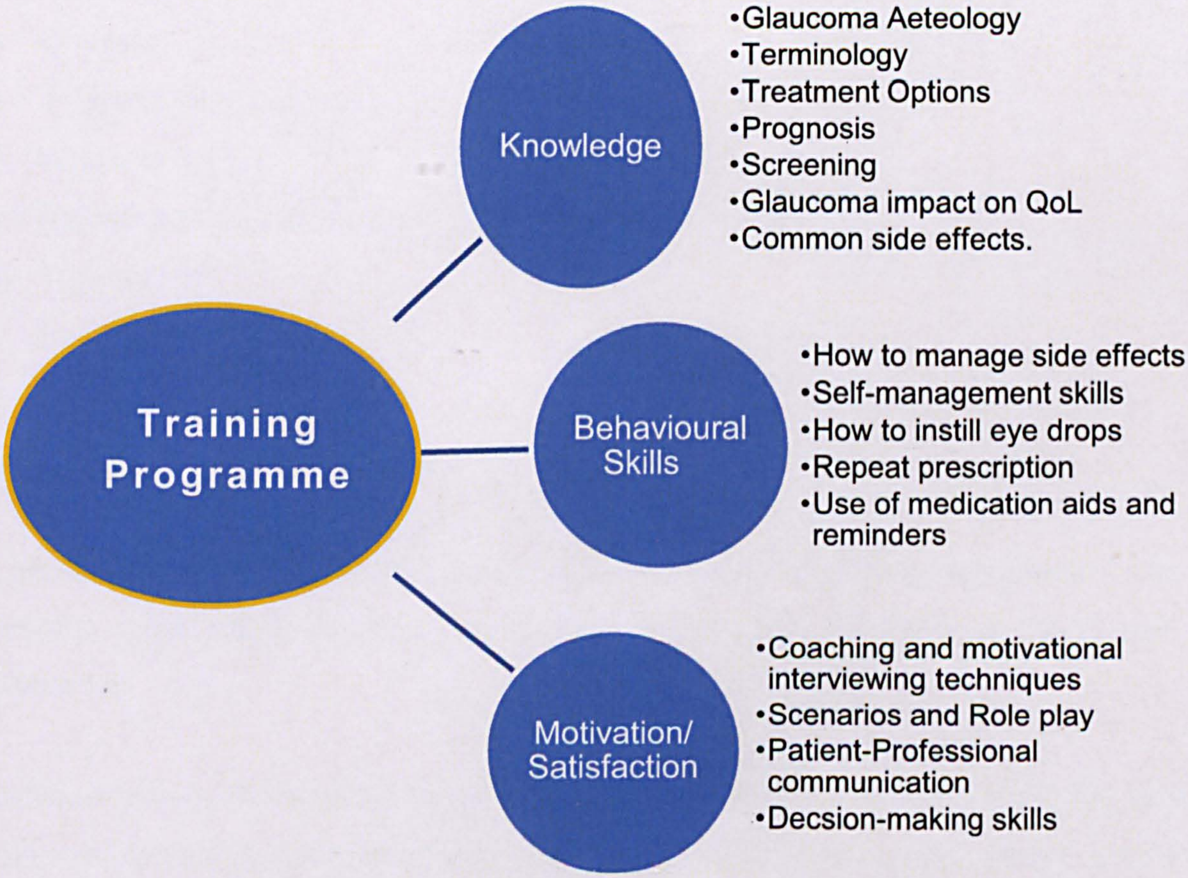
Expert Patient:
Drug non-compliance is a common problem. Avoid confronting the patient as the patient may deny it. Instead begin by asking if he has problems with the eye drops such as breathlessness or any problems applying them such as arthritic or rheumatoid hands. Then explain to him about deterioration of visual fields and the risk of blindness and losing his driving license. Suggest discussing alternatives with the doctor rather than not using the drops.

In this workshop, Expert Patients were thoroughly trained to deliver their respective intervention content before proceeding with the intervention. In addition to training on the delivery of the GEPP intervention, which included lectures, small group interaction, and extensive role play and other exercises, the GEPP training also included intensive exposure of Expert Patients to techniques previously demonstrated that facilitate and influence the learning of fellow glaucoma patients such as health coaching and motivational interviewing. Before the training began, Expert Patients were required to demonstrate mastery of intervention delivery to a pre-set criterion. Based on the pre-set criteria assessment, five Expert Patients were retained for the workshops.

A great emphasis has been placed on the knowledge and educational aspect of the workshops when recruiting and training the Expert Patients. To reiterate, to be deemed ready to deliver the intervention, Expert Patients were required to demonstrate a substantial understanding of glaucoma, excellent communication skills and abilities to motivate and encourage participants. Based on the IMB model (refer to figure 4.5) the Expert Patients Training Programme workshops were designed to take place over two days in a modern venue and covered the following topics:

1) Knowledge
2) Behavioural skills
3) Motivation/Satisfaction.

Figure (4.5): Contents of Expert Patient Training Programme based on the IMB Model.



The actual training delivered by the research team to the Expert Patients group will be discussed in detail in the following chapter as a cycle of the action research.

4.8 Compilation of Expert Patient Glaucoma Booklet

As part of the ethnographic component of the research, a 20 page booklet was designed that explained in simple language the main issues glaucoma patients may want to know about their condition. It was produced with input from the International Glaucoma Association (IGA) for the purpose of ensuring glaucoma patients had understanding of their condition and how to adapt to life with such a chronic condition. Although the language used is very simple, a glossary section has also been included to define medical terms used in the management of glaucoma.

This booklet was given to the Expert Patients as a reference to refer to once they finished the training workshops. A copy of this booklet was also given to all patients participating in this study including the intervention and control group participants.

The final version of this booklet comprised of:

- What is Glaucoma?
- Causes
- Types of Glaucoma
- Who is at risk?
- Patient pathway and diagnostics
- Treatments
- Eye Drops
- Driving and Glaucoma
- Self-management and Glaucoma.

This booklet provided much needed information for newly diagnosed patients who are sometimes sent home without any written information to read at their own convenience.

As outlined above, the booklet incorporates information about patient pathways and the diagnostic tests that are carried out on every visit to the clinic and rational behind doing so. Eye drop instilling is a critical issue in glaucoma concordance. Guidelines for instilling eye drops are demonstrated with photographs and side effects of eye drops. Explanations of the non-apparent indication for using eye drops are also presented in simple language in the booklet. In addition skills that are essential for self-managing glaucoma are presented to encourage patients to take control of their condition. Quality of Life issues that might be affected by glaucoma are also presented in simple language.

4.9 Section Summary

This section has presented the ethnographic approach that was used to address the phases and steps taken in developing the intervention and designing the training programme for the Expert Patients. It was important to keep an open mind and be flexible when approaching and delivering the training. As the Expert Patients grew in their roles and became more confident, there were adjustments to the way the intervention was delivered to the intervention group as will be discussed in the action research section, Part II. The following section will present part two of this study. Using a collaborative action research approach, the delivery and implementation of the interventions will be explicated.

4.10 Part II: Action Research

The second part of this study used a collaborative action research approach to implement the Glaucoma Expert Patient Programme (GEPP). This approach has ranged from "technical collaborative" in the early stages of this study and progressed to a "mutual collaborative" approach. In this section, the underpinning philosophy and an introduction to action research is presented. The aim and objectives of the study are explained, including the details of methods used for data collection and analysis, action research cycles are discussed and the methodological qualities and rational for its use with its ethical considerations are considered.

4.10.1 Collaborative Action Research

Action research has been used increasingly in different disciplines including community projects, education and health care (Hart and Bond, 1995). Many authors and researchers have used the term action research in various ways. To illustrate this, Reason and Bradbury (2001) reviewed phrases used interchangeably in chapter titles including: "participatory action research", "emancipatory action research", "pragmatic action research", "co-operative inquiry", "appreciative inquiry", "community action research", "action inquiry", "educational action research", "transpersonal co-operative inquiry" and "collaborative action research". Whilst these terms describe characteristics of action research and identify the essence of action research and the personal preferences of the philosophical paradigms that support it (Hope and Waterman, 2003; Munhall, 2011), inadvertently, they contribute to the confusion of classifying within the field of action research (Holter and Schwartz-Barcott, 1993).

Action research is considered to belong to a variety of schools. Within the constructivist/interpretivist school of thought, action research is viewed as a method of gaining access to participants' understandings and meanings of their situations (Hope and Waterman, 2003). Within the critical theory school, action research is recognised as a method to address ideological and power related issues in a particular situation (Kemmis, 2001).

A more recent and stronger addition is within the participatory paradigm school as it recognises the collaborative aspects of the action research method within an ecological context (Reason and Bradbury, 2001). This paradigm focuses on a concern for carrying out research that is *with, for* and *by* people and communities, rather than *on* them whilst putting peoples' participation and engagement at the heart of enquiry (Meyer, 2006). A feature that made this participatory paradigm very appealing was that it allowed patients to contribute in the design, delivery and evaluation of this programme. Its merits have been working with participants to identify problems in practice, implement solutions and to monitor the process and outcomes of change (Meyer, 2000a). The increased use and acceptance of action research as a legitimate form of enquiry according to Meyer (2000b) reflects its importance in understanding the complex factors in health care settings with a view to changing and improving practice.

The last three decades have seen action research evolving from a technical experimental approach to a more mutual and collaborative approach; then into an empowering and professionalising action research approach within nursing research as it seeks to achieve the status of a research-based profession (Holter and Schwartz-Barcott, 1993; Hart and Bond, 1995; Munhall, 2011). It also has been noted that the humanistic qualities of action research appeal to nurses who embrace action research as a collaborative enquiry rooted in reflective practice and as a natural fit for what nurses have been doing and continue to do (Hart and Anthrop, 1996; Shelton, 2008).

Nonetheless, many nursing researchers have realised the potential in action research to develop a transformative shift in nursing's culture whilst introducing innovation and facilitating change in practice (Waterman et al, 1995). There are numerous examples in the literature where action research was employed in health care research to generate knowledge and produce change. These examples include research that addresses professional issues (Kelly et al, 2002), producing change in hospitals and clinics (Parsons and Warner-Robbins, 2002; Shelton, 2008), assessing and improving education (Walker et al, 2001) and improving practice based upon patients' insight and experiences (Olshanky et al, 2005) as well as healthcare providers' feedback (Mitchell et al, 2005; Reid-Searl et al, 2009).

These examples demonstrate a change from a philosophy of doing things to people, to working with and supporting and enabling them to identify their own needs and facilitate formulation of strategies that will meet those needs. An emphasis on the importance of participation in the action research process is consistent with the emphasis in NHS policy to increase the active participation of service users in their care. Action research being used in health research has the potential to play a role in achieving the goals of the NHS as well as developing innovative practices and services over a wide range of healthcare situations (Waterman et al, 2001).

The methodological approach of collaborative action research was chosen as a suitable method for this research, in which participation was perceived as a means to an end; an educational process necessary to achieve change. However, in response to the political nature of conducting nursing research in the Trust, where clearly identified steps are a requirement for the approval of this study, meant a need for a shift in approaches. In the early stages of this study there was limited patient participation and input on how the research was designed and measurement of outcomes termed "Technical collaboration". However once the ethics and research and development committees approved the study, the approach shifted from the technical type, to a greater recognition of the patient participants' role as active players in the process. A more mutual and collaborative approach was employed to engage the Expert Patients in the processes of delivering the intervention according to the individual needs of the newly diagnosed COAG participants.

4.10.2 Definitions and Philosophical Perspective of Action Research

Considering the history of action research, it is not surprising that there are differing definitions in the literature (Waterman et al, 2001). In health care, action research has many applications as diverse as HIV/AIDS education in Tanzania, prisoners in Malaysia, improving care in nursing homes in Australia and the USA and NHS hospitals in the UK (Hughes, 2008). Therefore, it is understandable that there is no single definition or an agreed way of how to employ action research. For example, Kemmis and McTaggert (1990) provided an action research definition that includes the major components of an action research methodology including its ability of not only achieving a specific goal, but also generating new knowledge by studying the process of change. For the purpose of this study their definition of action research is used:

> *"a form of collective self-reflective inquiry undertaken by participants in social situations in order to improve the rationality and justice of their own social or educational practices, as well as their understanding of these practices and the situations in which these practices are carried out"*
>
> Kemmis and McTaggert (1990:5).

Hart and Bond (1995) on the other hand, devised a typology of action research that categorises the range of approaches to action research including: experimental, organisational, professionalising, and empowering. They set out criteria of seven main characteristics including: it has an educative base, it deals with individuals as members in groups, it is problem focused, it involves a change intervention, it aims at improvement and involvement, it involves cyclic processes and it is founded on collaboration. The strength of the typology presented by Hart and Bond (1995:38) is that it was developed to be *"...able to retain distinct identity of action research while spanning the spectrum of research approaches..."* it identifies explicitly characteristics of action research, clarifies action research types while avoiding problems associated with narrow definitions (Waterman et al, 2001).

In a large scale commissioned systematic review of action research by the English Department of Health Technology Assessments Research and Development Programme, Waterman et al (2001) provided a comprehensive definition of action research as:

> *"Action research is a period of inquiry, which describes, interprets and explains social situations while executing a change intervention aimed at improvement and involvement. It is problem-focused, context-specific and future-oriented. Action research is a group activity with an explicit critical value basis and is founded on a partnership between researchers and participants, all of whom are involved in the change process. The participatory process is educative and empowering, involving a dynamic approach in which problem identification; planning, action and evaluation are interlinked. Knowledge may be advanced through reflection and research, and qualitative and quantitative research methods may be employed to collect data. Different types of knowledge may be produced by action research, including practical and propositional. Theory may be generated and refined, and general application explored through cycles of the action research process."*
>
> (Waterman et al, 2001:11).

Whilst this is a lengthy definition, it does include the wide variety of approaches in healthcare action research. Most definitions in any discipline will incorporate three key elements:

- Its participatory nature, whereby researchers, practitioners and patients work together in directing the course of change and the accompanying research.

- Its democratic impulse, whereby all participants are seen as equals, have a voice in the process and are empowered to change the contexts in which they work together.
- Its simultaneous contribution to social science and social change (of knowledge which is argued to be more meaningful to practice) (Carr and Kemmis, 1986; Greenwood and Levin, 1998; Meyer, 2000b; Waterman et al, 2001).

Authors like Carr and Kemmis (1986), Reason (1994) and Hart and Bond (1995) have identified key characteristics of action research. After scrutinising all the characteristics, Waterman et al (2001) identified two main criteria as fundamental to action research and these have been included in their definition. These were: The Cyclic Process and The Research Partnership, which are described below.

4.10.2.1 The Cyclic Process

The action research project described in this chapter essentially proceeds through a spiral of cycles of problem identification including reflection, planning, implementation of change and monitoring, and evaluation, which leads to identification of new problems, planning, action and evaluation and so on (refer to figure 4.6). Each of these activities is systematically and self-critically implemented and interrelated (Masters, 1995; Waterman et al, 2001).

Figure (4.6): Illustration of the cyclical process of action research adapted for the GEPP project, from Susman and Evered (1978).

East and Robinson (1993) argued that the increasing popularity of action research presented as a cyclical process in nursing research might be partly attributed to its similarity with elements and phases of the nursing process. However, as with the nursing process, I found applying the action research steps not always as straightforward as they appear on paper. It is with planning the actions and preparations for the intervention stage of the cycle where this research has been most challenging. As stated previously, during the planning phase, particularly, there were some logistic challenges that limited patient input and participation.

4.10.2.2 The Research Partnership

Action research, unlike traditional research, involves those who are being studied, whether they are practitioners or clients, as co-researchers (Waterman et al, 2001). It considers participation as fundamental to an overarching aim to promote more democratic research practices, where participants perceive the need and importance of change and are willing to assume an active part in the research and the change process (Meyer, 2000a). Waterman et al (2001) argued that participation in action research turns the conventional research wisdom of neutral and independent researchers on its head. Traditional research that relies on controlling variables when dealing with human beings in complex organisations, have failed to address uncertainty, complexity, instability, uniqueness and value conflict (Greenwood, 1984).

4.10.3 Why Action Research?

Action research as a methodology provides a real opportunity for professionals and researchers, who are trying to acknowledge and respect the contributions that potentially can be made by service users, to become jointly involved in the research process. Action research is a means to discern new knowledge; particularly for those frustrated by traditional research methods based on quantitative analysis and control. Indeed, the challenge of COAG provides a classic example of the need for a collaborative approach. In relation to the patients' experience, their experience of managing their COAG should not only be acknowledged, but also the findings studied so that they can be integrated within the service to improve the way services are provided. Through the collaborative approach it becomes possible to engage with professionals and patients to improve the experience of newly diagnosed glaucoma patients.

Pietroni (1998) argued that conventional health research has been helpful in detecting trends within populations and the physical process involved in disease progression. However this research methodology does not itself address the patient experience from the patients' perspectives. Hughes (2008) observed that the so-called "Gold Standard" of RCTs has failed to provide an insight into such problems and falls short in defining and supporting credible effective practice. More than 200 variables have been studied in RCTs addressing glaucoma, but none can be considered as consistently predictive of adherence/compliance (Vermiere et al, 2001). These methodologies (conventional and RCTs) have failed to address the requirements of service users who do not engage in the scientific discourse. Therefore it has not addressed issues associated with the patient experience. The more collaborative approach of action research that engages patients as well as professionals will potentially provide a better understanding of the issues associated with the patient experience; particularly in relation to adherence and concordance in glaucoma self-management.

Health professionals and service users face problems and challenges in their daily practice that require systematic and rigorous examination that cannot be made sense of through conventional methods of positivist scientific medical scrutiny. Rather, it is evident that service users have been viewed as passive and relatively powerless consumers of knowledge that is passed down to them. Thus, it became evident to me there was a necessity to develop an active rather than passive research tool that involved patients alongside professionals in a positive and ethical process of raising awareness so that adherence and concordance in self-managing COAG could be achieved.

In addition, in health care practice, with the ever increasing gap between the aims of practice and theories that supply them, many practitioners have found in action research a philosophical approach to bridge this gap by drawing on patients and practitioners' involvement and experiences. As Schwartz and Walker (1995) observed, there is a growing separation of the management of professional work from the work itself, creating a need for better understanding of health care service delivery. Owen (1993) observed that in British nursing research, action research has increasingly attracted considerable attention and is perceived as a highly compelling way of bridging the gap between theory, research and practice (Owen, 1993). It has also been advocated as a method that empowers nurses through the supportive collaboration of researchers and the researched (Webb, 1989).

It is from these notions where the "new paradigm" unconventional research comes into place and is partly constituted by action research in health care practice. It is the active engagement and passionate involvement of all participants in an action research inquiry that makes action research so recognised in bringing to life the people and purpose for which the research is designed.

Professor Waterman and colleagues proposed five reasons for choosing action research. These were found in 48 British reports and are:

- Action research is about encouraging stakeholders to participate in making decisions about all stages of research, or empowering and supporting participants (most common reasons);
- Action research solves practical, concrete or material problems, or evaluates changes (frequent reasons);
- Action research contributes to understanding knowledge or theory; has a cyclical process including feedback, and/or embraces a variety of research methods (reasons associated with the research process);
- Action research educates;
- Action research acknowledges complex contexts, or can be used with complex problems in complex adaptive systems (quarter of reasons) (Waterman et al, 2001).

4.10.3.1 Generating Knowledge and Understandings

Central to all research is the generation of new knowledge, and action research is no exception (Hart and Bond, 1995). However, action research generates knowledge that is directly related to people lives, work and practice (Holter and Schwartz-Barcott 1993; Meyer 2000b). Indeed it is the philosophy underpinning action research that educates, liberates, empowers, supports and emancipates research participants that makes the knowledge generated of great relevance and importance (Hart, 1996).

In their review, Waterman et al (2001) observed that generation of knowledge, theoretical and practical, is considered by half of studies reviewed as important. More importantly, there has been an emphasis and priority given to the personal and professional development of participants. This research is no different. It is a tailored self-management programme designed to be delivered by Expert Patients to newly diagnosed glaucoma patients. Participants' development and empowerment has been crucial for the development and implementation of this research as patients have been involved in most phases of this process. Straight after receiving the approval, Expert Patients were invited to comment on the content of the intervention and the mode of delivery as part of the planning phase. Interactive sessions were held where Expert Patients engaged in role-play and scenarios designed to boost their confidence in interacting with patients appropriately. Participation generated great interest amongst Expert Patients in the research and established a constructive relationship with myself. This relationship has grown stronger and has enhanced a sense of ownership and empowerment amongst Expert Patients that has solidified their commitment to the successful completion of this research.

4.11 Research Aim and Question

As stated in Part I of this chapter, this research is the first of its kind to be undertaken in an ophthalmic context. Considering the degree of flexibility in answering the research questions, action research was determined to be the method of choice for Part II of the research as it enables adaptation to changing circumstances as the research process unfolds. Action research methodology is a vital, dynamic and relevant approach to enhancing change. It is argued that action research methodology is a way to bring about sustainable services that evoke human flourishing (Koch and Kralik, 2006).

The overall research question for this research can be formulated as follows:
"Does the development and implementation of a GEPP improve knowledge and concordance amongst newly diagnosed glaucoma patients?"
The objectives of this part of the study pursued in order to answer the research questions are:

1. To determine through semi-structured interviews peoples' (Expert Patients, Patient Participants and staff) perception of the GEPP.
2. To determine through questionnaires whether knowledge and concordance improved immediately following exposure to the GEPP.
3. To determine overtime whether knowledge and concordance are maintained.

Given the complexity of this inquiry, a variety of quantitative and qualitative methods were used at different stages to gather data that formed the cycles of the action research processes and eventually provided the findings of this research. Methods used were mostly of a qualitative nature including observation, individual semi-structured interviews, focus groups and reflective field notes. Additionally, questionnaires were used to measure before intervention and after changes to participants' levels of knowledge, satisfaction and adherence. Issues arising during different stages were fed back to Expert Patient participants and the Steering Group.

4.12 Participants and Participation

As Noted in Part I of this chapter, this study took place in three glaucoma outpatient clinics in Moorfields Eye Hospital NHS Foundation Trust. During the course of this study the research had input from different groups at different stages as explained earlier. Additional to the groups involved in the ethnography phase, the action research phase has involved two more participants groups; Intervention Group (n=25) and Control Group (n=25).

It was not feasible to include all members of staff involved in running this service in this inquiry. Therefore only people whose patients were at the heart and focus of this inquiry were involved. It was primarily designed around the patients felt needs expressed and delivered by Expert Patients. Their participation and input was paramount to the success and completion of this inquiry.

4.12.1 Intervention Group

A total of 25 clinic patient recruits that met the inclusion criteria on their clinic visit were included in the study if they agreed to participate.

- *Inclusion criteria for clinic patient participants*

a) Diagnosed with COAG within the last two years: as this is the period where patients need knowledge and support most. (During the first visit the patients are overwhelmed with the amount of information given by clinic staff and understandably their anxiety levels are expected to be high. Therefore, little knowledge is retained);

b) Aged 18 years or over: COAG is uncommon in childhood and most common amongst adults over the age of 40. In addition, only adult patients over the age of 18 years attend these clinics;

c) Agreed to be interviewed to obtain essential demographic information and complete a glaucoma knowledge questionnaire prior to receiving training by an Expert Patient;

d) Agreed to be contacted on the next visit (6 months follow up in the clinic) and by phone once (1 - 3 months after the initial contact) for monitoring purposes and to complete the following questionnaires: glaucoma knowledge, medication compliance and satisfaction with the treatment;

e) Agreed to participate in the research.

- *Exclusion criteria:*

a) Diagnosed with COAG longer than 2 years;

b) Under the age of 18 years;

c) Unable to fully understand the patient information and/or consent form;

d) Unable to comply with study follow up to 6 months.

4.12.2 Control Group

A total of 25 newly (up to two years) diagnosed patients with COAG attending the same outpatient clinics as the intervention group were invited to take part in this research as a control group. The same inclusion and exclusion criteria as the Intervention Group were followed when recruiting the Control Group. They were asked to complete a set of four different questionnaires including a demographic questionnaire, knowledge questionnaire, satisfaction questionnaire and adherence questionnaire. These questionnaires were repeated on 1 and 3 months and 6 months. Patients were given the opportunity to ask questions about the questionnaires and the study in general, though they did not receive any intervention other than the regular information that is provided by the doctors and nurses in the clinics.

4.12.3 Involvement of Expert Patients

The participation of Expert Patients was crucial to the success and the completion of this research. It was a delicate situation that needed a sensitive and flexible approach that would ensure their preparedness and commitment to this unusual role they were about to take. This required striking a strong partnership between me as a facilitator of the research and the Expert Patients who would deliver the intervention and work with fellow patients. Efforts were made to ensure enough training and constant support was provided so as to boost their confidence and make them feel at ease engaging with other patients. Collaborative mechanisms included frequent meetings and informal contacts with the Expert Patients as to changes that needed to be made and data to be collected on the basis of emerging findings. These meetings, most of the time, included the Expert Patients and myself. We discussed the progress of the research and their progress and they raised issues that had emerged either in the research or themselves.

Following delivery of the workshops I met regularly with the Expert Patients to reinforce consistency of intervention delivery and to deal with any implementation issues. Intervention fidelity and consistency were high across all interventions. The interventions were designed to be relatively easy to apply in existing care practices followed in the clinic settings. The Moorefield's Eye Hospital NHS Foundation Trust Research and Development Ethics Committee approved all intervention procedures.

The Expert Patients lived in different areas of the city and some of them led a busy life. Therefore, it was critical to arrange for their attendance around their busy work lives and commitments. Allocating each Expert Patient to a particular outpatient clinic closer to where they lived was imperative to make the most of the time they dedicated to this research. It was also important to look after their welfare and in a sense not to exhaust them. For instance, on a particular day the Expert Patient chose either a morning or an afternoon session and attended for no more than 3 to 4 hours. Expert Patients were always asked if they were feeling comfortable to start their session. I asked them to let me know the day before if for any reason they could not attend. For example, one of the Expert Patients had a fire in her house during the night. Everything was burned and she had to be hospitalised for a few days due to minor injuries and then had to be relocated to an emergency accommodation. We had to put her part of the research on hold, for almost two months, before commencing her role again in the research.

4.13 Delivering the GEPP to the Intervention Group by the Expert Patients.

The second cycle of this research started on completion of the Expert Patient training. As indicated previously, each Expert Patient was allocated to one particular outpatient clinic on a morning or afternoon session according to their availability. The Expert Patient delivered each session during the patients' visit to the clinic whilst they were waiting to be seen by the ophthalmologist.

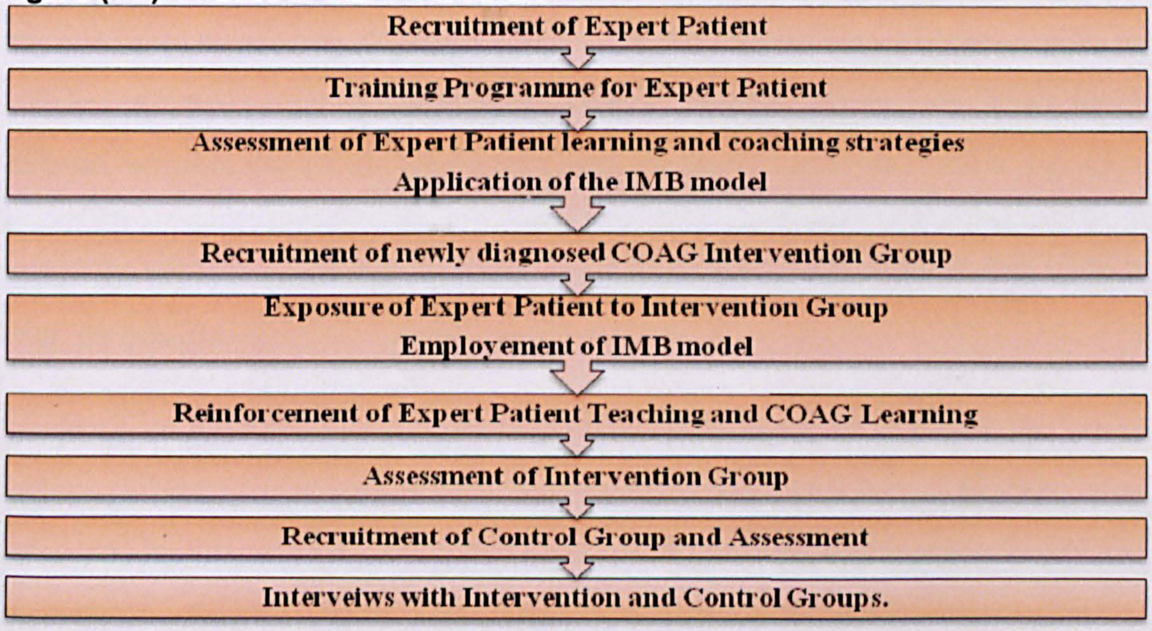
The idea behind such an intervention supports the notion of patient-to-patient interaction where the newly diagnosed patient will benefit from the vast experience shared by the Expert Patient. Lorig and Holman (2003) argued that self-management programmes delivered by lay volunteers have shown favourable results in comparison to professionally led programmes.

Twenty-Five clinic patient participants were recruited and received the intervention whilst attending their routine clinic visits. I approached all the participants and explained to them the idea of the research and provided them with an information sheet to help them make an informed decision whether to take part in the research. Those who agreed were asked to read and sign the consent form, then to complete the demographic questionnaire. Clinic Patient Participants were then introduced to the Expert Patient as a patient having glaucoma for many years and attending the same service. The participants were assured that this session would be conducted within the time usually spent waiting (usual waiting time is one to two hours) to be seen by the Ophthalmologist. This helped to eliminate any distraction that could impact on the quality of the discussion as the patient felt at ease because they were not missing their turn whilst they were with the Expert Patient.

Each session started with the Clinic Patient Participants completing the knowledge, satisfaction and adherence questionnaires respectively in the presence of the Expert Patient and myself. This was followed by a few questions and casual conversation with the Expert Patients so as to build rapport with the participants. The session ideally lasted between 30-45 minutes. However, some sessions lasted more than an hour. In cases where patients were having problems instilling their eye drops, the Expert Patient demonstrated the right technique of doing so and asked the participants to perform the same technique which was time consuming at times. In other cases where participants had certain health beliefs that the Expert Patient had to challenge, a very constructive conversation continued for close to 80 minutes. However informing and essential, due to time constraints doctors and nurses have in seeing patients through the clinics, it is unfeasible to hold such a lengthy conversation with each patient. This is where the GEPP has been effective and makes a difference. The Expert Patients have the time to interact with the Clinic Patients whilst the Clinic Patients are waiting to be seen.

Depending on the time spent with each participant and availability of patients who were interested in taking part, recruitment of Clinic Patient Participants took place over a period of 3 months. Each Expert Patient was expected to deliver the intervention to 5 to 6 patients. However at the beginning of the research, one Expert Patient withdrew from the study, which meant the other three Expert Patients had to deliver the intervention to 8 or 9 participants. The following Figure (4.8) presents a flow chart of the stages of this study.

Figure (4.7): Phases of GEPP Flowchart



4.13.1 Reflective Field Notes and Feedback from Expert Patient

During the implementation phase, informal discussion with the Expert Patient participants and the training team were recorded. Reflective field notes based on Expert Patients' actions, performance and feedback were kept. Field notes were recorded throughout this phase and continued until the end of follow up with the participants. Frequent discussions were held with staff involved in running the clinics to obtain their opinion of the study as it unfolded.

After every session the Expert Patient spent with the Clinic Patient Participants, I would reflect on that session with the Expert Patient. We considered things we could improve or adjust to make efficient use of the time spent with the Clinic Patient Participants. Examples of such adjustments included changes in the environment to minimise distraction levels. Keeping the patient's clinical notes with me was another example, as Clinic Patient Participants frequently asked to see their visual fields results once they understood what the visual field was and why they were required to undertake this particular test routinely when attending the clinic.

4.14 Trustworthiness of the Action Research Process

Quality in action research and qualitative methods in general has created an extensive debate. Some writers suggest that the quality of action research can be judged solely on the 'professional judgement' of the action researcher (Rolfe, 1998). Other authors have called for judging the quality of action research against an approved checklist. Guidance is clearly needed to give the new nurse action researcher a structure within which their work can be developed (Meyer, 2000b). Waterman et al (2001) have offered specific guidance (questions) for funding agencies, policy makers, ethics committees and researchers for assessing action research proposals and projects within the present healthcare climate. However how extensive this guidance is followed may be questioned.

As a new action researcher I found these questions helpful in enabling me to look at the cycles of this research in a different way and look for ways to improve the progress of this research. My 'professional judgement' was not at its best and not completely developed when the study was initiated, therefore I found it reassuring to critically reflect on the guidance and ask myself these questions. During the planning phase, this guidance helped me to provide clear answers to the Research and Development Committee who were in favour of conducting an RCT. The following list shows the questions that Waterman et al (2001) compiled and I reflected upon:

1. Is there a clear statement of the aims and objectives of each stage of research?

2. Was the action research relevant to practitioners and/or users?
3. Were the phases of the research clearly outlined?
4. Were the participants and stakeholders clearly described and justified?
5. Was the relationship between researchers and participants adequately considered?
6. Was the research managed appropriately?
7. Were ethical issues encountered and how were they dealt with?
8. Was the study adequately funded/supported?
9. Was the length and timetable of the research realistic?
10. Were data collected in a way that addressed the research issue?
11. Were steps taken to promote the rigour of the findings?
12. Were data analyses sufficiently rigorous?
13. Was the study design flexible and responsive?
14. Are there clear statements of the findings and outcomes for each phase of the study?
15. Do the researchers link the data that are presented to their own commentary and interpretations?
16. Is the connection to an existing body of knowledge made clear?
17. Are the findings transferable?

Murphy et al (1998) and Waterman (1998) identified a number of practices that can enhance the validity of qualitative research and provide the reader with detailed information needed to evaluate the trustworthiness of the findings. Meyer (2000a) added that, whilst acknowledging subjectivity and the inherited problems of validity in action research, one should not seek objectivity but instead demonstrate freedom from bias. Hope and Waterman (2003) highlighted that validity in action research revolves around:

> *'.... The dialectal movement between action and reflection....as a consequence, needless vagueness and ambiguity is reduced, but amplification and deepening of the research focus is enhanced'* (Hope and Waterman, 2003:125).

This will include the different ways participants were involved in data collection and analysis, the processes used to feedback findings and a clear account of how findings were subsequently refined. These practices have been followed closely in this study, and a detailed description has been given on the methods used for data collection, analysis and the impact of an action research approach. These descriptions have been underlined by reflexivity; particularly in relation to my role as an action researcher and the Expert Patients.

Titchen (1995) highlighted in action research that it is critical to be aware of using your own beliefs and values consciously through a high level of self-awareness and simultaneously representing the experience and evaluation of those participating in the research. This can be achieved through reflexivity and field note keeping as part of challenging oneself in light of differing opinions. This has helped me immensely in attempting to use a critical perspective when approaching issues arising. Such a perspective recognises the identification and subsequent exploration of tensions and contradictions within oneself and in the field study (Waterman, 1998).

4.15 Section Summary

The second part of this study presented in this chapter has explored issues arising from designing, and implementing a glaucoma self-management programme GEPP. The study is located in the participatory paradigm that incorporates inquiry that is with, for and by people and that privileges practical and theoretical knowledge. In an inquiry of this nature, participants were collaboratively involved in research activities and decision making that has previously been viewed as being in the domain of the researcher alone. An in-depth relationship between study participants and myself was necessary for such practical knowledge to emerge.

4.16 Part III: Mixed Methods

The third part of this chapter describes the mixed method approach associated with the evaluation and interpretations of the GEPP. For the purpose of presenting this Thesis the evaluative phase is presented here but the reality is it was an on-going process starting toward the beginning of the research. An array of data collection tools where used to evaluate the effectiveness of the GEPP including field notes, patient interviews and questionnaires.

4.16.1 Background and Definitions

Historically, the decision as to whether a qualitative or quantitative method would best answer the central questions of a study would be dictated by the hypotheses or research question. A sound research project would require using the most appropriate method(s) at the appropriate time (Morse and Field, 1995).

The interest in mixed method design has grown over the years as questions related to healthcare have become more complex. Mixed method research combines elements from both qualitative and quantitative paradigms to produce converging findings in the context of complex research questions (Lingard et al., 2008). The surge in mixed methods use in health care research is viewed by some noted researchers as recognition of some of the inherent limitations and strengths of both qualitative and quantitative approaches (Tashakkori and Teddlie, 2003). Many scholars argue that the demands of an increasingly complex health care system and the needs of both health practitioners and patients have long called for new approaches to health service research (Clark, 2000).

Combining the two research methods (qualitative and quantitative) in health care services research is by no means a straight forward procedure, with large amounts of literature that consider the conceptual and pragmatic feasibility of mixing multi-methods (Sofaer, 1999). Several definitions of mixed methods in health care are available in the literature. Morse and Field (1995) argued that it is more than simply collecting qualitative data from interviews or multiple types of quantitative data from questionnaires and surveys. It should start with gathering evidence based on the nature of the research question and theoretical orientation. Whilst Johnson et al (2004) explain it is the intentional integration or combination of qualitative and quantitative data to maximise the strengths and minimise the weaknesses of each type of data. Of the many definitions available in the literature and for the purpose of this Thesis, mixed methods research will be defined as a methodology that:

1) Focuses on research questions that call for real life contextual and cultural understandings;

2) Employs quantitative research to assess the magnitude and frequency of the constructs and qualitative research to explore the meaning and understanding of constructs;

3) Intentionally integrates or combines methods to draw on the strengths of each; and

4) Frames the investigation within philosophical and theoretical positions Creswell et al (2011).

The incorporation of qualitative research methods is increasingly seen as a valuable and necessary component of health care research that intends to improve health care service (Rundall et al, 1999). Robbins (2001: 27) a noted ethnographer, argued that *"rigorous qualitative research can provide the 'why' behind statistically significant differences".* Qualitative research, as discussed earlier, has been increasingly used for the rich descriptions of the context and that of complex phenomena (Kaufman, 1994). Sofaer (1999:1101) argued that qualitative inquiry allows for *"Initial explorations to develop theories and to generate and even test hypotheses while moving toward explanations".* Crawley et al. (2000:2518), a noted quantitative researcher, stated that *"qualitative research is needed to clarify and improve the knowledge of health care professionals of the demographic, socioeconomic, psychosocial, and medical factors that influence decision regarding patient care".* In contrast, as Denzin and Lincoln (1994:4) put it *"the quantitative approach emphasises measurement and analysis of causal relationships between variables, not processes".*

4.16.2 Mixed Method Design

The study described in this section is a mixed method of sequential exploratory design. According to Creswell et al (2003) this design is characterised by the collection and analysis of qualitative data followed by the collection and analysis of quantitative data. Priority is given to the qualitative aspect of the study and the findings of the two phases are then integrated in the interpretation and evaluation phase.

This part of the Thesis will present the integrated mixed methods design used to explicate the findings and the interpretations of this inquiry. Throughout this study, evaluation and reflection were on-going starting as early as June 2009 and continued until January 2011 when data collection ceased. Data collected included but are not limited to: Expert Patients' actions, feedback and views on the progress of the research and their experience, Clinic Patient Participants views and learning and interviewing staff about their thoughts on the research step by step. This added to the accumulative data that was being fed back during the process of doing the research. My analysis therefore of this action research was on going.

4.16.2.1 Field Notes

Fields notes were produced from attending frequent meetings with the Consultant Ophthalmologist running the clinics, my research supervisor and subsequent interviews with staff involved in the clinics. Field notes made from observing Expert Patients role play in the training days helped me to comment on their performance and further evaluate how engaging and effective they were in delivering the intervention. Further notes were taken during the delivery of the intervention. For instance, on one occasion in one of the busy sessions in a clinic, three glaucoma teams were working at the same time. It was overcrowded with limited space for staff to attend to the patients. The project team involving the Expert Patient and myself moved to the canteen. After the session started I observed that a clinic patient participant was distracted by the noise in the background and soon realised this environment was not fit for purpose as it had a lot of distraction with people coming in to get something to eat. I had to find another site for the Expert Patient to deliver the intervention. This twist in the process and subsequent changes illustrates how important flexibility in the method and approach used must be.

Comments and feedback made by Patient Participants on the performance of Expert Patients and their thoughts regarding the research were taken in form of field notes. These comments have provided insight into the overall evaluation of the Expert Patients' delivery and their suitability for this role.

4.16.2.2 Expert Patients Interviews and Questionnaires

Semi-structured interviews were used to capture the views of Expert Patients on their experience and the role they played in this research. Expert Patient involvement in chronic eye diseases is a particularly under-researched area where participants' views are not known. Therefore, getting a sense of the predominant views of their experiences was essential. Further interviews were employed toward the end of the research to gain more insight into how beneficial they felt the intervention was. All interviews were tape recorded and transcribed verbatim. In addition, three questionnaires were used to assess knowledge and understanding of glaucoma compared to baseline data obtained prior to their training. The questionnaires were approved by the Research and Development Committee and validated which made it impossible to alter any of the contents of the questionnaires.

4.16.2.3 Intervention Group Participants Interviews and Questionnaires

The impact of the intervention was measured in two ways, completing a set of three questionnaires and the second in semi-structured interview. Of the questionnaires used, two were well validated and gained Research Committee approval. The third questionnaire was extensively used in measuring glaucoma patient adherence and also gained Research Committee approval. The first questionnaire assessed patients' knowledge and understanding of glaucoma; designed by Hoevenaars et al (2008). A few minor changes were made to make the language more applicable to British patients. It measures improvements on level of knowledge and how much information patients gained and whether the GEPP helped them to better understand their condition and treatment. The second questionnaire assessed patients' satisfaction with the treatment regimen and the service they received. It was designed by Day et al (2006). A few minor changes were made to the layout to make it more reader friendly with a bigger font size for ease of reading. This questionnaire assesses, for those patients who gained knowledge of their condition, whether the GEPP made any difference to their level of satisfaction. The third questionnaire, a self-report adherence level to treatment regimens, measured whether knowledge improves satisfaction and adherence levels.

Baseline data were collected from all participants on the recruitment day prior to receiving the intervention with an Expert Patient by completing the pre-designed and piloted questionnaires. Follow up data were obtained by completing the three questionnaires at patients' clinic appointments at 1 and 3 months as well as 6 months. If this was not possible, the questionnaires were sent in the mail for the participants to complete and return to me. The questionnaires used are composed of closed questions which is acknowledged may not provide in-depth data. Extra space was provided for patients who were willing to comment on the questionnaire and their experience. Expert Patients also completed these questionnaires prior to the training received and at the end of this research.

The time used to complete questionnaires was troublesome for a few patients whose ability to read is impaired due to glaucoma. Expert Patients helped patients, when needed, by reading out loud questions to the patients and providing explanations that did not influence their answers. A few patients found completing the questionnaires on recruitment time-consuming. This made them reconsider their decision to take part in the research. For example, on one occasion a clinic patient participant withdrew from the study as he found completing the questionnaires too time-consuming.

Of the 25 participants, 10 were randomly selected to be interviewed so as to shed more light on their experience with the GEPP and how it helped them to better cope with their COAG. The interview took anything between 20-40 minutes and covered the following issues:

- Experience with COAG,
- Quality of Life and COAG;
- Their views on the running of the clinic and staff;
- The delivery of the GEPP (convenience, relevance and usefulness);
- The IMB constructs (knowledge, satisfaction and concordance)
- Self-management and coping skills developed;
- Things they would like to change and improve in service and in the GEPP.

4.16.2.4 Control Group Participants Interviews and Questionnaires

The control group completed the same set of questionnaires mentioned above on their visit to the clinic on baseline, on 1 and 3 months and 6 months. To measure for changes over time the control group was recruited concurrently with the third follow up of the intervention group data collection. Although there has not been any indication of changes taking place to the practices followed in the Trust clinics than before the study began, since this study took 18 months to complete, it was seen as important to measure for any potential changes with the intervention group and compare it with the control group. Of the 25 participants, 10 participants were selected to give their feedback and views in semi-structured interviews. The interview covered the following issues:

- Diagnosis and patient pathways;
- Experience with COAG;
- Experience with the service and staff involved in running the service;
- Importance of constructs of IMB (Knowledge, satisfaction and concordance);
- Things they would like to improve or to see improved.

4.16.2.5 Staff Interviews

Staff interviews were held at different stages in this study. For example, at the exploration phase, interviews were conducted to gain views on practices followed in the clinics, content of the training programme and so forth. A member of staff who has been involved in running educational programmes highlighted problems encountered in her experience and ways of overcoming them. These problems were examined carefully with the Consultants and Expert Patients when designing the GEPP. At the end of the study, two Lead Nurses running the clinics were interviewed to reflect on the patients' recruitment period and the Expert Patient intervention. These interviews were more focused and structured.

4.17 Methods of Data Analysis

As mentioned earlier, findings described in this study were collected using a mixed method approach including the following: individual semi-structured interviews, focus group interviews, observation, field notes and questionnaires. Qualitative data provided information and understanding on process and implementation of the Expert Patient Programme, whereas quantitative data collection instruments measured for the impact of the GEPP, sustainability of the GEPP over time, and trends in the findings. In this study, data were collected continuously throughout the various phases. The emerging findings were pondered for meanings and interpretations as well as prompting further data collection or adjustments on the planned actions. As I grew in confidence and became more experienced these mini-cycles became a more naturally conducted series of processes.

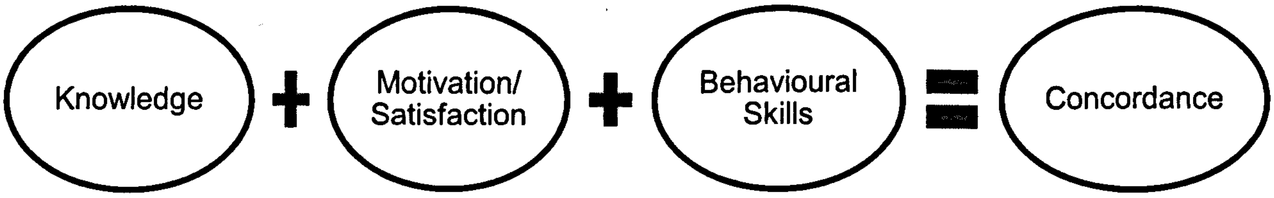
4.17.1 Thematic Analysis

During the exploratory phase in each of the outpatient clinics, a qualitative assessment describing and assessing health care practices followed. In this phase, the work of Susman and Evered (1978) functioned as a guide in the procedure of thematic analysis. The same procedure was used for the qualitative evaluative phase of the research. This procedure involves a cyclical process consisting of three stages in which each informs the direction of the other.

Stage One, describing, begins with the process of data collection and serves as a means of linking the work with the remaining analysis. The process includes engagement and familiarisation with the data as it is transcribed from a verbal form into a written form. It also includes reviewing all the thoughts that involve field notes and discussion memos regarding the possible direction of the data analysis. Stage Two, organising, begins the process of arranging data collected into codes in marginal notes. This consists of using a data-driven approach to identify codes in the marginal notes. Codes are simultaneously identified during the organising stage and explored to identify underlying patterns that lead to the formulation of linking concepts and constructs. Stage Three, connecting, involves the search and creation of themes from the concepts and constructs identified in Stage Two by noting connections between codes. In this stage, the data are translated into themes about the elements and components of the glaucoma self-management programme in order to present the research findings in a meaningful way with clear distinctions between themes.

Thematic maps of the data presenting a summary of the main themes and patterns will be explained in detail in the following chapter. Table 4.3 shows a working example of the way themes were constructed to reflect the IMB model.

Table (4.3): Qualitative Analysis worked example according to Susman and Evered (1978).

<table>
<tr><th>Marginal notes: (Codes)</th><th>Statements from Interviews: (data driven narrative)</th></tr>
<tr><td>Know – Knowledge
Things to do – Knowledge</td><td>“By knowing things you accept them quickly”IG07.</td></tr>
<tr><td>Knowing – Knowledge
Accept – Motivation</td><td>“So I want to know if there is anything I can do to stop me from going blind” IG05</td></tr>
<tr><td>Consequences – Motivation</td><td>“So the more info I get the more likely I will follow the instructions and the happier I am” IG04.</td></tr>
<tr><td>Follow instructions – Behaviour
Happy – Motivation
Take drops – Behavioural</td><td>“It (knowledge) motivates me to take my eye drops on time knowing what the consequences are” IG03.</td></tr>
<tr><td></td><td>(IG = Intervention Group Participant)</td></tr>
<tr><td colspan="2">Concepts (Leading to constructs)
Know+ things to do + knowing = Knowledge
Consequences + Happy + Accept = Motivation/Satisfaction
Take drops + follow instruction = Behavioural Skills</td></tr>
<tr><td colspan="2">Constructs
Knowledge
Motivation/Satisfaction
Behavioural Skills</td></tr>
<tr><td colspan="2">Main Themes (IMB Model)
 </td></tr>
</table>

4.17.2 Descriptive Quantitative Statistics

Data extracted from the patient group (Expert, Intervention and Control) questionnaires were coded and entered onto statistical software SPSS (Version 18.0). Each patient was given a code and individual score for questionnaires completed. The Demographic data questionnaire in addition to the three previously mentioned questionnaires have provided ordinal level data which when entered into SPSS allowed for making comparisons between baseline, first follow up and evaluation when merging the three data sets. Non-parametric tests were used to compare groups including Mann-Whitney *U* Test and Wilcoxon Signed-Ranks Test. The aim of the statistical analysis was to identify changes on the scoring of each patient throughout the study and establish trends throughout the data. Any comments made by participants on the questionnaire have been treated and analysed as qualitative data. A statistician has examined the data set for any missing data or errors made during data entry and analysis. Expert Patients, Intervention and Control Groups participants were assigned a unique identification number (not their hospital number) so that they cannot be identified.

4.18 Ethical Considerations: A Summary

In preparation for seeking ethical approval, my supervisors and I were engaged in discussions with the Research and Development Department at the Trust to obtain their approval and support for the research. Moorfields Eye Hospital NHS Foundation Trust is a predominantly medical institution with very little if any recognisable nursing research contribution. There were conflicting interests amongst the Trust Research and Development Ethics Committee Panel (which approves all research prior to review at the main Ethics Committee) on the way the study was designed, the contents of the training programme and the way the study would be evaluated as previously indicated. It was agreed this study would be a mixed methodology (qualitative and quasi experimental quantitative design) comprising a before-and-after study involving a collaborative action research where outcomes would be measured on one, three and six months follow up with a view toward a large scaled RCT in the future. The Research and Development Department had a growing interest in using Quality of Life (QoL) measurement and their level of anxiety amongst participants in this study as outcomes to evaluate the effectiveness of this programme. However, it was agreed that QoL and anxiety questionnaires would not capture the effect of this intervention, which is improving concordance, and level of knowledge of glaucoma patients. Therefore QoL tools and tools that measure anxiety were not used.

4.18.1 Ethical Approval

Ethical approval to undertake the research was granted by the Moorfields Eye Hospital NHS Foundation Trust and the Whittington Hospital Research Ethics Committee. Prior to Trust approval, NREC approval was obtained. This is a process in which NREC ensures that the rights, safety, dignity and wellbeing of research participants are protected, and facilitates ethical research that is of potential benefit to participants, science and society. In addition, approval to undertake the research was granted by the City University, London Senate Research Ethics Committee and indemnified for £3,000,000.

4.18.2 Consent Form

Crucial to the ethical conduct of research is informed consent. All participants in this study were adults over the age of 18 and able to give an informed and considered consent to participate. Prior to any data collection, participants involved in this study were given information sheets. One sheet was to inform Expert Patients and one sheet was for other Participants (refer to Appendix 7 and 8 respectively) and participants were asked to indicate whether they understood:

- The purpose of the research;
- How the data collected would be used;
- Who the researcher was;
- How the research would be conducted;
- How confidentiality would be maintained;
- That participation was voluntary and that they could withdraw at any time without fear of any adverse consequences.

Once a patient felt confident and willing to take part in the study, a consent form was signed with one copy given to the patient, one kept in the participants' medical records and one kept in the Trust Nursing Office. The patients' General Practitioners were informed in writing that their patients were involved in the study.

4.18.3 Confidentiality and Anonymity

Data provided by individuals as part of the research study were safeguarded and remained confidential to the research team and were used only for the purposes of the research. Unless agreed in advance with the research participants, individuals providing data were not personally identifiable in any outputs that arose from the research. All information was collected and stored in accordance with the requirements of the Data Protection Act (1998). All measures were taken to protect patient confidentiality and anonymity. However, where Expert Patients were involved with the other fellow patients in the clinics, the ethical issues became more complex. Although participants gave informed consent, it was relatively unclear how the study would unfold as recruitment progressed. This is a common occurrence in action research; therefore, each situation as it arose was considered and the best interests of Expert Patients as well as clinic participants were maintained.

Meyer (2000b) noted that confidentiality and anonymity are potential problems to be explored with participants in action research projects. It is likely that in action research researchers will talk about things that might be personal or confidential. It was important to discuss how much of the discussion that took place in team meetings with the Expert Patients was to stay inside the group and what was permitted to be conveyed to others outside the team. Since this study involved Expert Patients interacting with fellow patients in the clinics, I could not control what participants said to each other in the field and as such, vulnerability of individuals could have become an issue. Anonymity and confidentiality may be compromised by the fact that the Consultant Ophthalmologist and I can be easily associated with having worked in the glaucoma service during recruitment and data collection. Therefore, many people within the organisation and within the same service reading the finished Thesis may be able to identify the key players and Expert Patients in this study.

4.18.4 Objectivity: Influence on the Research

The issue of objectivity is challenging for researchers. The researcher's status as an insider or outsider will provide opportunities as opposed to constraints to the success of the study. On the one hand, as an insider researcher, there is the risk of 'taken-for-granted assumptions' remaining unchallenged and, on the other, how the 'strange' world encountered by the outsider researcher is engaged with and made intelligible

(Hockey, 1993). As an insider researcher I was an active observer of the events and the phases of this study unfolding. Having spent the last seven years working at the Trust I developed a good understanding and appreciation of the context of the study in a way that is not open to an outsider researcher. Insights and sensitivity to things both said and unsaid and to the culture operating at the time of the research are all potentially available for me as the insider researcher.

As stated previously, in preparation of this study I was allowed to observe and work in the glaucoma service which enabled me to short cut much of the mutual familiarisation phase necessary to seek out common ground, and establish a positive research relationship. I knew and was known to the staff involved in running the clinics and would be involved in facilitating the recruitment and delivery of the intervention at later stages. Such a position was a privileged one which was essential to the success of this study. It also helped me to anticipate problems before they occurred. For instance, one of the sites where we planned to recruit half of our sample was extremely crowded and occasionally staff used poorly equipped rooms due to lack of space. I expected this would be an issue I would have to deal with, and thusly made contingency plans to use another site to recruit patients, which required some logistic preparation.

4.19 Conclusion

This chapter has presented the approach followed in designing, implementing and evaluating the GEPP. This study is located in the collaborative paradigm that incorporates inquiry that is with, for and by people and that privileges practical and theoretical knowledge. In an enquiry of this nature, participants were collaboratively involved in research activities and decision making that has previously been viewed as being in the domain of the researcher alone.

The aim and objectives of this study, along with details of the methods used for data collection and analysis, and quality assessment issues including ethical considerations have been comprehensively provided in this chapter. The following results chapter describes the final phase in which general findings will be explored.

CHAPTER FIVE

Exploring Findings from Designing, Implementing and Evaluating the GEPP

The following chapter is presented in three main parts. Part one presents the findings from the ethnography conducted in the exploration phase. Part two presents the findings from implementing the GEPP through action research methodology which includes demographic findings from the Expert Patient Group with its action cycles. The third part of this chapter provides the detailed mixed methods evaluation of the implementation and effectiveness of the GEPP.

5.0 Introduction

It may be remembered from chapter 3, that the GEPP is based on the IMB model (Fisher et al, 2003). The primary causal mechanism of this programme is changes in the main constructs (Knowledge, Motivation/Satisfaction and Behavioural Skills) which is likely to lead to changes in self-management behaviour and subsequently improving health outcomes which in this case is better COAG concordance.

Self-management programme evaluation has rarely used a qualitative approach. Instead it has heavily relied on experimental design to provide assurance of how effective these programmes have been. The GEPP, however, has been evaluated using a mixed methods design. The quantitative findings reflect trends and show how participants' learning processes have evolved and been maintained during this programme. The qualitative findings extracted from semi-structured interviews and other forms of data collection provide a picture of the participants' responses to the illness itself and to the GEPP. As noted previously, the sample size of this study was relatively small and therefore, results should be cautiously interpreted.

5.1 Ethnography Results

Designing the GEPP required a great understanding of the problem of COAG as a chronic debilitating condition. It also required an understanding of the daily running of the glaucoma service and patient pathways, the needs of glaucoma patients;

particularly at early stage of diagnosis. Furthermore understanding had to extend to the perspectives of patients and professionals in relation to how much of their needs and care is being met in the clinic, how best to fill gaps in expectations and needs and the constraints that healthcare providers are likely to face.

5.1.1 Context Issues in Managing COAG in Outpatient Clinics

Unlike many countries round the world, the UK's NHS is experiencing an increase in the proportion of elderly people living well into their 80s and 90s. These demographic changes have led to an increased demand for health and social care services to be redesigned to ensure they can meet these demands. Like most other chronic conditions, COAG incidence increases with age; with the majority of patients attending the glaucoma clinic being in their 60s 70s 80s. One clinician stated:

> *"As you can see most patients attending the clinic are elderly who are either hard of hearing or with limited mobility or other health conditions... So it does take longer time and more efforts than if you are dealing with younger patients..."* (OP01).
>
> (Refer to Table 5.1 below for key of the numerical codes).

Table (5.1): Key to numerical codes.

OP	Ophthalmologist/Optometrist
NM	Nurse Manager
ON	Ophthalmic Nurse
EP	Expert Patient
IG	Intervention Group
CG	Control Group

Social factors are driving the changing perceptions and changing expectations which mean that an increasing number of older people rightly want choice and control over the care they receive and the services they use, including the location in which this takes place. Service redesign to ensure person-centered planning and self-directed support will be vital to delivering a personalised service and maximising people's choice and control, thereby meeting these expectations.

> *"Unlike years ago, patients nowadays are more aware of their rights and so you find them asking questions and wanting to know why you're doing this and why you're doing that..."* (NM01).

One clinician added:

> *"I personally like it when patients start asking questions and weighing options when it comes to treatment regimens...It means they are interested and most likely they will take things on board..."* (OP02).

Despite the increased pressure on staffing as a result of this noticeable increase in the age and number of patients attending outpatient clinics, the staffing level has remained largely unchanged and is likely to remain so. Subsequently, NHS leaders have advocated for meeting these demographic changes by developing innovative models of care for older people to satisfy the demand.

> *"...As you know only two staff nurses are employed full time in this clinic, the rest of them are either part time or working somewhere else and just doing over time..."* (NM02).

5.1.2 Under Pressure and Patient Pathways

The glaucoma outpatient clinics start running at 7 every morning and run up until five o'clock in the evening. They are generally very busy clinics and most often would be over booked so as to meet the large numbers of patients referred to the Trust. Early in the morning the nurses prepare the clinics, the clerical staff check the list of patients and update the team on the numbers of attendees and whether there are any cancellations or changes that may disrupt the running of the clinics. On arrival patients are registered by clerical staff; then soon after are seen by an ophthalmic nurse for an initial assessment, which includes a brief history and visual acuity assessment, and determination of what tests need to be done on the day. Then most often the patient will be called to have a visual field test done by a technician or Healthcare Assistant. Shortly after that the patient will be called again to have an Intraocular Pressure test and his pupils dilated so he/she can be examined by the Ophthalmologist.

As mentioned earlier, as the clinics were getting busier and more patients were waiting for assessment (whether initial assessment by nurses or final consultation with the ophthalmologist or optometrist); there was an increasing pressure on the team to speed the flow of patients. This has increased the workload on the staff and put clear time constraints on staff. Consequently, consultations were getting shorter in duration. From the staff point of view, with the limited spaces available, it meant at times two nurses were seeing two patients at the same time in the same cubicle. For instance, on one side of the room a nurse was examining patient eyes using the slit lamp and on the other side of the room another nurse was assessing the visual acuity of a patient. When asked what they thought of that, a nurse replied:

> *"You can see how long some of the patients have been waiting for. Unfortunately we can't expand the space we have here, so we try to make use of every possible space to speed things up and get the patients through"* (ON01).

Other nursing staff expressed a similar view:

> *"...Even if we can get more staff, there is no space for them to see patients. We only have three cubicles for doctors and two cubicles for nurses and that is not enough given the number of patients we see here on daily basis"* (NM02).

Lack of space is a persisting problem in the Trust outpatient clinics; in particular the glaucoma outpatient clinics. With an ever increasing number of patients, the comments made above applied to one particular site (Upney Lane site) and to a lesser extent to the main glaucoma clinic at City Road. The leading glaucoma consultant running this clinic is well aware of the situation. There is a plan to relocate the clinic to a near site which can accommodate the increasing numbers of patients. OP01 added:

> *"In our last meeting I raised the issue of space and I am aware of a plan to relocate to another site nearby...We will be able to employ more staff to cope with the workload of this clinic"* (OP01).

On other sites like City Road, the problem of limited space is more prominent, and the prospect of expanding is very difficult due to the aging building at City Road which led the executive board at the Trust to consider relocating the entire hospital. These plans were mentioned in one of the clinician comments:

> *"The lack of space has always been an issue at Moorfields...We know the building is very old and cannot accommodate the increasing numbers of patients...This is the case in all services at Moorfields..."* (OP03).

When asked if this issue impacts on the quality of care and patient experience in the glaucoma clinic, OP02 commented:

> *"To some extent it does...We recently opened a new branch at Loxford Clinic...rooms are larger...pleasant waiting area...patients are full of praise and they keep saying it feels like a private clinic...So in a way it does make them happier..."* (OP02).

The staff in all the outpatient clinics included in this study were under pressure to cope with the workload and large numbers of patients attending.

> *"We never have enough time; because there is not enough staff...I think that is one of the main problems. We know what we need to do and how we can do it but physically we have not got the time to do it, and we know for a fact that we're not doing enough for the patients. We don't tell them everything; not out of negligence, but because of the lack of staffing and time to spend with them" (NM03).*

This aids the argument of positive associations between better staffing and better patient outcomes. The evidence of the impact on quality of consultation and supporting self-management and organisations of having too few nurses is clearly visible in this quote. Therefore, the EPP could bridge these gaps and complement the care provided by professionals.

From a patient point of view, for some, it felt quite uncomfortable to be seen with relatively limited privacy. As this patient put it:

> *"...At times it is (the clinic) chaotic and you don't feel at ease at all..."* (CG02).

For other patients who are more claustrophobic the experience was quite unpleasant because of the small spaces and dark rooms. As this patient put it:

> *"...It feels like you have been shovelled in a cupboard..."* (CG03).

5.1.3 Quality of Consultation and Care Provided by Professionals

This research assessed the quality of the consultation and the information shared with patients attending the clinic. A checklist (see Table 4.2) was designed for this purpose in which I asked thirty patients a set of questions as they were leaving the clinic to establish their level of knowledge and understanding of their condition. The data extracted from this checklist were analysed based on the IMB model as follows:

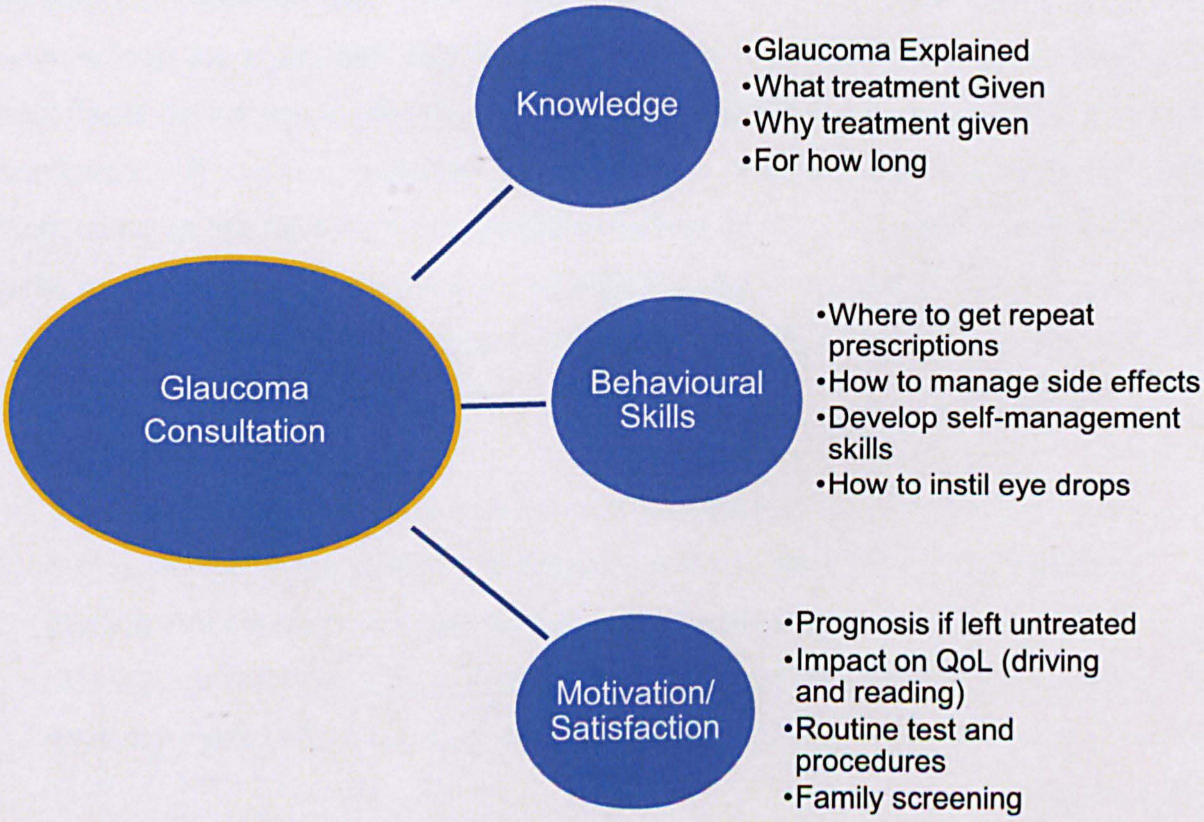


Figure (5.1): Observation data analysis based on the IMB model.

5.1.3.1 Knowledge

Of the 30 patients questioned, more than half (53.33%) indicated that they did not "receive an explanation of their condition" by health professionals and/or "were not sure what glaucoma is". 76.7% of participants said they were "given treatment to be used until the next visit but did not know how to use it properly". The rest (23.3%) said they were not "given any treatment at this stage" or that they were "not sure they were given treatment". For example, when asked was treatment given? A clinic patient answered:

> *"I am not really sure. He (Ophthalmologist) looked at my eyes and said we will give you drops to use every day. Then he spoke to someone and she looked at me and said I am not sure if you need them (eye drops) and that was it, nothing was said after that"* (CG04).

For those patients that received treatment the question asked was, whether it was explained to them what the treatment was for and why they must use the eye drops. Of those responding two thirds (65.2%) indicated that they "did not know" or were "not sure why the treatment was given". One third (34.8%) of the respondents were "not sure how long the treatment" was to be used. More importantly, one third (39.1%) of respondents did not know what to do if they ran out of drops or "where to get a repeat prescription". A further question often asked between professionals on the effectiveness of the treatment in preventing further damage was if it was to be taken exactly as prescribed. Some patients realised the reality of COAG, that sometimes it cannot be controlled even if the treatment is taken exactly as prescribed and the IOP is lowered. As this patient expressed:

> *"I know I have glaucoma and have high pressures in my eyes hence I am taking the eye drops to keep the pressure low. But the doctor I saw last time told me that even though I am taking my drops and being careful I could still develop some further damage, which I don't understand. Why? Or if there is anything more I can do to stop further damage"* (CG07).

This reflects some of the uncertainties surrounding the effectiveness of the treatment and the impact that it could have on concordance when managing COAG.

5.1.3.2 Motivation/Satisfaction

When asked about the importance of treatment and the consequences of not strictly following the treatment, only one third (36.7%) of patients seemed familiar with the seriousness of the consequences of not using their eye drops and leaving their glaucoma untreated. In particular, they were not aware that as the glaucoma progresses they are likely to develop visual field defects; whereby their ability to drive will decline and that subsequently they will have to give up driving. More than two thirds (73.3%) of those who responded were not informed about this consequence.

- **Case Study (From Field Notes)**

This is the case of a 55 year old male taxi driver (drives for living). He was diagnosed with advanced COAG and advised to take eye drops for the next few months and to return for review in three months. This gentleman didn't attend for three consecutive visits and subsequently was discharged from the service. Two years later he was back in the clinic after being referred back by his GP, and as he explained he understood that the drops were to be used for one month only. He went abroad for a few months. On this visit, the visual field test showed a progressive field loss that potentially will limit his ability to drive and loss of his main source of income. This was terrible news that was not expected and not well received by this gentleman. It will essentially have a significant impact on this gentleman and his family's main source of income. Perhaps this could have been prevented had this gentleman understood the importance of taking the eye drops and potential damage that could result if ignored and if he had come back for his review. Without pointing the finger at who is to blame, there was an evident breakdown in communication. It may be that a language barrier was an issue that was not addressed. The patient may well have been told everything but unfortunately he did not understand it.

5.1.3.3 Self-Management and Behavioural Skills

When asked if patients knew about a set of self-management skills that are essential for patients to know about in order to help self-care for their glaucoma, only (23%) of the participants were familiar with the skills and thought they were able to self-care for their condition. Amongst respondents only 3% were told about self-management skills and the rest indicated that nothing was mentioned about self-management skills. When asked about genetic testing for the condition, amongst respondents (86.7%) indicated that they were “advised to get family members screened for glaucoma”; particularly those “over the age of 40”.

One essential skill when managing COAG is the ability to instil eye drops correctly. Asking patients to demonstrate instilling eye drops is a subject that tends to be overlooked.

- **Case Study (From Field Notes)**

This case presents a 65 year old lady who had been diagnosed with COAG over the last two years during which she did not attend her appointments on three occasions. The patient only attended one follow up appointment. I took interest in this case and phoned the patient asking her the reason for not attending and convinced her to attend a specially arranged appointment the following week. Fortunately this time she attended. As this lady tends to travel often she doesn’t remember to get repeat prescriptions, and if she does she tends to forget to take her eye drops with her. She has very limited knowledge of COAG and the potential damage it carries with it. After a long discussion with this lady I asked her if she can instil her eye drops confidently, she hesitantly answered:

> *“Sometimes I get them in my eyes and sometimes on my cheek”* (IG14).

During demonstration, in 9 out of 10 try’s the patient instilled the drop on her lid or cheek. This case represents a lack of knowledge/skills and led to the lack of interest, not attending appointments and subsequently not using the eye drops correctly and potentially risking her sight. A lengthy conversation followed on how to use the drops, to carry them when travelling and how to use a Drop Aid. I asked this lady to return following two weeks of practice. When I saw this lady again she was a confident and happier lady because she was doing the right thing to save her sight. This patient is mastering the dropping far better now as she said:

> *“Now I don’t have that constant guilt in me that I am ignoring the advice and now that I am doing the right thing I feel so much encouraged to visit the clinic to see what my pressures are like and how I am doing”* (IG14).

5.1.4 Expressed Patient Needs

Analysis of the interview data found that the majority of patient respondents, as explained earlier, lacked an understanding of their condition and therefore, had plenty of unanswered questions and doubts that were not addressed by professionals. During this ethnography I asked participants what information and skills they considered as essential for self-managing their condition. The answers were varied and personal to some extent, however, there was general consensus that basic understanding of the condition that is being treated, why it is treated, prognosis if not treated, what they need to do to help their condition, glaucoma and quality of life and driving were the main themes. Skills they also wanted to learn include: instilling eye drops, how to minimise side effects, how to remember using their drops and getting/need for repeat prescriptions. Additionally, a few participants; particularly those of a younger age were finding it difficult to accept this condition due to some doubts they had that were not addressed. Therefore, they were more reluctant to use their medications.

As noted previously, this research set out to explore the issues arising from the development, implementation and evaluation of a new and innovative Glaucoma Expert Patient Programme (GEPP) in an outpatient setting. In the narrative that follows, the findings of the before-and-after GEPP intervention in the three main constructs; knowledge, motivation/satisfaction and behavioural skills (adherence), amongst the three participant groups (Expert, Intervention and Control) will be presented. This will involve explication of qualitative and quantitative data. Qualitative data is articulated in participants' narratives and the quantitative data from the questionnaires delivered on 1st and 6th months follow up is analysed and depicted descriptively.

5.1.5 Expert Patients: Understanding and Respecting Roles

When building a multidisciplinary team it is essential to understand and respect individual roles as this may impact communication and contribute to poor teamwork. Therefore, once ethical approval was granted to start recruiting patients, it became essential to explain to professionals running the outpatient clinics the role of the Expert Patient and what we would be trying to achieve during this study. Brown and Greenwood (1998) indicated that a lack of recognition from team members about an individual's contribution to the whole could leave a feeling of demoralisation. Subsequently, there could be the potential for failure of the programme.

The Expert Patients' role was central to the completion of this study and to the delivery of the intervention. The role was carefully clarified and explained to staff involved in this study. Initially, as one of the nursing staff commented in one of the focus groups:

> *"So we don't have to explain anything from now on to patients, Expert Patients will be doing all the talking"* (ON03).

This comment prompted me to clarify that the research was only an exploratory study at this stage and Expert Patients would not take away any of the traditional responsibilities of the health professionals for providing high quality care. The outpatient clinic manager commented:

> *"Even though there will be an Expert Patient on site speaking to other patients, this should not affect the usual running of the clinic and the care we provide our patients. The liaising will be directly between Raed (I) and who is in charge on the day"* (NM01).

One of the inclusion criteria to become an Expert Patient was to have been diagnosed with glaucoma for more than 10 years, as with time patients are likely to gain more experience and become knowledgeable about issues that face the glaucoma patient in their daily life. One of the Expert Patients commented:

> *"I think it was important to receive this training as I discovered that there are things I don't know about glaucoma even after 20 years of having it. Also it prepared me what to expect from patients and what sort of questions they ask"* (EP04).

The training programme intended to prepare the Expert Patients to deliver the intervention. I thought the training went well and Expert Patients were motivated and excited about their involvement in this research.

> *"The training went quite well. Participants were very engaged and enjoyed most of it. Though I think we needed more role play sessions to give participants more opportunity to practice more." (Field Notes- August 2009).*

One of the Expert Patients commented on the training programme:

> *"The role plays were excellent. The venue was very pleasant, and the presenters were very knowledgeable and friendly"* (EP01).

Another Expert Patient added:

> *"Having been diagnosed a few years ago, I found that the training and discussion were helpful to me to understand the problem of glaucoma"* (EP02).

A booklet designed for the research was also helpful in enforcing the information given in the clinic and also provided the patient with something they could read at their convenience.

As one of the participants said:

> *"I really wanted to know more (about glaucoma) but did not know where to find information so I just 'Googled' it and read there...But some time ago I found a good leaflet here in the waiting area (Clinic) so I took it home and read it"* (CG07).

One of the Expert Patients suggested, producing a DVD to incorporate issues outlined above. It should present the potentially damaging and sight threatening complications of glaucoma and would be far more effective in reaching all disadvantaged groups.

> *"I thought a short video on glaucoma on a DVD that the patient could share with family and carers would be helpful and their involvement*

> *might be crucial in ensuring that the patient complies with their treatment"* (EP01).

5.1.6 Enhancing Self-Management

As discussed earlier, the time spent with the patients was limited with professionals and so it was essential for the Expert Patients to be motivated to deliver the intervention to fellow patients to self-manage their condition. Whilst health professionals were likely to mention patient education groups and associations like the International Glaucoma Association (IGA), they utilised written information such as an explanatory sheet on what glaucoma is if available. Ophthalmologists used long-term prognosis as a motivation strategy whilst nurses were more likely to engage in more active teaching if they had the time. A nurse manager commented:

> *"...since we opened this branch and I am the only nurse running the clinic and that is several months now... I used to spend a lot of time going through different aspects of self-managing glaucoma with patients...but here it is very difficult to speak to people much about glaucoma as most of the time I have too much to do..."* (NM01).

She added:

> *"I can't see something better than someone who is actually experiencing the problem, have family and people and connection to do with glaucoma and have to use drops and been through pathways of glaucoma. The best person possible to speak to another patient is a patient who is being diagnosed with glaucoma"* (NM01).

A City Road clinic manager commented:

> *"...I am occasionally involved in sort of one-to-one sessions with glaucoma patients having trouble managing their conditions. Unfortunately I often have to come out and cover for other nurses or the clinic is over booked and we have many patients waiting. Then my priority becomes to attend to those patients waiting to be seen..."* (NM03).

Patients rarely mentioned any experience of being taught by professionals on a one-to-one basis, however, the one exception is when the City Road clinic manager is running her teaching sessions. Apart from these rarely run teaching sessions, there is no other condition specific group education to enhance self-management. In fact only a few of the professionals involved in the study could actually describe the Department of Health Self-Management programme or suggested to any patient the EPP.

In contrast, Expert Patients had clear ideas of strategies to enhance self-management amongst patients with COAG. They knew what helps and what doesn't, what is essential to know what is not as one of the Expert Patients commented:

> *"...It is the practical daily tips of living with glaucoma, how not to forget your eye drops, where to store them, how to fit them in your daily activity of doing your shopping, cooking your dinner; getting ready for bed. That is what will make the difference and what will help most..."* (EP02).

5.2 Action Research Findings

In this part of the chapter, data generated from the implementation of the GEPP and action research cycles involved will be presented.

5.2.1 Recruitment of Intervention Group

Recruiting participants for the intervention group required the presence of myself and the Expert Patient in the clinic. On any particular session, I would come to the clinic an hour before the first appointment; assess all the clinical notes of the patients on the list of that day, decide who is eligible for participation and who is not, and then make my own list of participants and potential participants. We did not always have clinical notes of patients on site, so until I asked a patient a few questions I would not be able to decide if he/she was eligible. Then before the clinic started I would meet with the Expert Patient and plan our day around the appointments of potential participants. As soon as the patients arrived at the clinic I approached them and introduced myself and told them what the study was about then asked them if they would like to take part in the study. I always offered them time and an information sheet to consider and to help them make up their mind before committing to participation in the study. Patients tend to spend between 1 to 3 hours per visit, so that gave me enough time to recruit the participants and for the Expert Patient to deliver the intervention without causing the participants any unnecessary delays. Once a patient considered the information sheet and agreed to take part, the consent form was completed and then he/she was introduced to the Expert Patient who normally waited in a separate room to deliver the intervention.

The recruitment procedure seemed like a straight forward procedure, but following the inclusion criteria meant we could only recruit newly diagnosed patients with COAG. This meant fewer patients met our inclusion criteria. In other words, there were occasions when we (I and Expert Patient) attended the clinic to recruit participants but after considering the clinical notes of patients found none of them met the inclusion criteria which meant four hours were spent without any recruits. On other days, I made my list of potential participants but none of them agreed to take part, which meant spending four hours at the clinic and not recruiting any participants. This was particularly frustrating for one of the Expert Patients who had to travel over an hour on the train to get to the clinic. She voiced her frustration and commented:

> *"It's a shame that we cannot decide before hand if there are patients who are eligible to take part or whether they are willing to take part, as this could save us a lot of time instead of travelling miles...It feels like a wasted opportunity..."* (EP01).

For other Expert Patients this was not an issue as they lived locally and coming to the clinic as a volunteer was always a gain for them. They got to meet the professionals who usually looked after them when they were attending for their glaucoma appointment.

As most glaucoma patients attending the clinic were elderly, they were often accompanied by relatives (i.e., son or daughter) and/or siblings. It was important to allow both the patient and carer or sibling to decide with the patient whether to participate. At times patients were keen to get involved and the carer was not as keen. The decision at the end was to not to take part.

On a particular case I wrote in my field notes:

> *"...When I approached Mr. X to invite him to participate, he was quite keen to get involved and he liked the idea and wanted to learn more about glaucoma. To my surprise, his daughter who was reading a magazine, turned to me and said 'no my dad knows everything and does not want to learn more, do you dad?'..."* (Field Note).

A lack of space was one the main problems we faced during recruitment. At times I had to cancel the entire day as there was no free space for us to use to speak with participants and for the Expert Patient to deliver the intervention. One of the outpatient clinic managers commented:

> *"In this clinic, we have a terrible lack of space and sometimes we have to share the same cubicle, so I think you will find it difficult to find the space that you can use for recruiting patients. Maybe you should try other outpatient clinics...."* (NM02).

5.2.2 Intervention Group Experience with COAG

This section will present the data illustrating the experience of the intervention group participants of living with COAG. The majority of the narrative begins with the pre-diagnosis phase, optometrist and General Practitioner referral and the pathway followed at the Trust. The effect on life and quality of life will be conveyed and the section will conclude with narrative on how participants reacted to being diagnosed and strategies to cope with COAG.

5.2.2.1 Diagnosis; Shock, Denial and Validation

Receiving a diagnosis for many participants was a complete shock as often they did not have any signs or symptoms prior to being diagnosed.

> *"It was a bit of shock really, you know. I saw my optician for new glasses and the next thing I am here with glaucoma. I still don't think I have any problem with my eyes...you know. I can see perfect and have no pain or anything..."* (CG06).

For others it was confusing and worrying that they were unable to decide whether they have COAG or not

> *"I didn't really know anything about it before they told me. The optician was not sure what he saw and here in the clinic they are still not sure if it is glaucoma. So the whole thing is confusing and not right"* (CG01).

> *"Well that is the thing. They told me at the beginning that I have not got glaucoma. Then the next visit they said you do have glaucoma and we will give you some eye drops to use. Then another doctor saw me and said no (there is no glaucoma) but nothing has been confirmed as yet"* (CG05).

For younger patients, being diagnosed with glaucoma was not only shocking but a reality they denied and found unacceptable.

> *"You know it's been 18 months now since I was first referred; now they are saying that I have glaucoma and I should take these eye drops for life or I go blind...You know I am still 28 and none of my family had it... I don't believe what they saying... It's all confusing"* (CG06).

CG06 added:

> *"I have faith in Jesus and if I have glaucoma, Jesus will heel my eyes not these eye drops. If anything they made my eyes worse"* (CG06).

For others, the diagnosis was something they predicted and the diagnosis brought a sense of relief that it could be controlled by taking eye drops and that they were not going blind.

> *"I didn't find it shocking to be honest, because both of my two sisters had it, the younger and the older sister, I am the middle one. So I knew I would get it at some point. I think I am even lucky. I didn't get it as early as they did..."* (CG07).

> *"I think I was lucky that they probably picked it up early and I have very little problems in terms of you know, controlling the pressures with the drops"* (CG03).

5.2.2.2 Adapting and Adjusting "Quality of Life"

It is widely accepted that during the first two years of life with any chronic condition patients tend to develop strategies of coping. The diagnosis is considered to be a disruptive event in some cases and to a lesser extent to others as COAG is largely asymptomatic and patients do not experience any symptoms at this stage unless it is discovered very late.

The impact of COAG varied between respondents but at the very least the glaucoma would have some impact on their life plans. For many the thought of losing their vision and becoming blind was frightening and terrifying whilst others spoke of their experience with COAG as part of life's journey.

The majority of participants involved in the interviews considered COAG as a non-disruptive event and hardly noticed any changes apart from taking their eye drops on a regular basis and coming to their clinic appointment every six months.

> *"I think I have very little problems with managing my glaucoma. I come for regular appointments to which ever clinic I am meant to be coming, and every time they say the pressure is well controlled and there is no damage at the back of my eyes...apart from having to do the drops every night I don't think it (COAG) has affected my life a lot"* (CG03).

For working participants, COAG has not limited their ability to continue working as participants added:

> *"It has not really affected my life at all. I am still working full time and I am driving as usual, go swimming every now and then and you know no problem at all"* (IG02).

> *"...though I have noticed that before this (being diagnosed) I would be looking at the tele without my glasses and see clearly, but now I am finding it a bit blurry when looking at the tele without the glasses..."* (IG04).

> *"I am still doing my shopping and driving although I am 68, so I would say that it (COAG) has not stopped me from doing my usual things and going out and about, though I only had it (COAG) for 10 months"* (IG02).

Managing the condition and the daily use of the eye drop/drops was considered by the majority as hard work and the reward they got for the effort was the sense of control when they had a low reading of IOP and so minimising the damage to their eyes. For others the eye drops had troublesome effects that made it almost impossible to continue using the eye drops. Many symptoms were reported as having impacted on their outlook and quality of life.

> *"I am still doing the drops but I am not sure if they are doing much to be honest...as they make my eyes very gritty crusty and red especially in the morning which is something I never had before...But the doctor says they seem to be working and controlling the pressure"* (IG02).

> *"I didn't have any symptoms at all until I started using the eye drops... that's why I was not very convinced at the beginning"* (IG01).

For other respondents the appearance of their eyes was very important and strictly taking their eye drops meant they would have red and crusty eyes; something they were prepared to tolerate:

> *"...the inconveniences of doing these drops for all this time...as you can see my eyes are always gritty and red, you know my colleagues at work keep asking what's wrong with your eyes. Or are you alright? It is really annoying"* (CG06).

> *"...my eyes were absolutely fine until I started putting them drops, what they called, Travatan or something like that. You know when I drop them in my eyes they sting like mad...and look at my eyes they are always red, very crusty and I really don't think these are doing me any good"* (CG06).

Some patients were offered alternative eye drops to try, but the side effects seemed to be no better:

> *"I told the doctors last time that the eye drops didn't agree with my eyes as they sting a lot...They said they would like me to try some other drops to see if it improves things...They gave me a new drop but if anything it is worse"* (IG03).

In terms of long term adjustment to their conditions, Expert Patients were trained to identify coping strategies developed by participants. As the GEPP is planned to be delivered within the first two years of being diagnosed the chances are all participants will be at an early stage of trying to integrate the illness into their lives. The most common form of management technique described by participants was the use of medication, however, Expert Patients were able to elaborate on any other self-care practices they may have tried so as to be considered in the intervention delivered to the patients.

5.2.2.3 What will happen to me? Am I Going Blind?

Many respondents reported going through a period of anxiety regarding the effectiveness of the treatment they were taking and considered the future of their eyes, they simply kept asking:

> *"Am I going blind?"* (IG01, 03, 04; CG04, 06, 12).

For the majority who follow the treatment regimen and attend their appointments the answer will be 'no'. For some unfortunately, the answer will be 'yes'. If COAG is discovered in the late stage and patients do not strictly follow their treatment, there is a strong chance that they will go blind at some point.

> *"Ever since my mom went blind because of glaucoma, I am always frightened the same thing will happen to me and I won't find anyone to look after me…it is scary though"* (EP03).

5.2.3 Delivery of the GEPP by Expert Patients (Employment of IMB Model)

Unlike other generic EPPs the GEPP in essence incorporated individual needs as expressed by participants and an intervention that was delivered by Expert Patients accordingly. As discussed previously, prior to each session I provided the Expert Patient with a brief ophthalmic history for each participant in addition to participants' responses on the knowledge questionnaire to be considered in the shape of the intervention to be delivered. Nonetheless, maintaining a consistent intervention that addressed the three main constructs of the IMB model; knowledge, motivation and behavioural skills was equally essential. That meant for knowledgeable participants, the focus was more on behavioural skills and the motivation necessary to achieve concordance. For less knowledgeable participants it was important to provide factual information that may contribute to improved concordance.

5.2.3.1 Complementing Existing Self-Management Routines (Knowledge and Coping Strategies)

It was essential for the intervention not to disrupt the coping mechanisms participants had initiated. Instead it had to complement them and provide further practical tips that will enhance their coping and self-management.

One of the Expert Patients commented during the training:

> *"I think we should be very careful not to sound judgmental and critical of the participants' way of coping. Instead we should complement that and share our experience and ways of self-managing..."* (EP01).

Often these coping strategies needed some adjustment; it was vital that this adjustment was planned and approved by the participant and that the participant understood the justification for doing so.

One participant commented after completing a session with an Expert Patient:

> *"...I struggled at the beginning to get the drops in my eyes, and then I started looking in the mirror to get the angle right...sometimes it went in and sometimes it didn't...she (Expert Patient) gave me this little dropper which seems very easy to use...I will definitely try it and see how it goes..."* (IG03).

As can be seen, the participants had attempted to manage their condition; sometimes using a trial and error approach in an attempt to find a way that worked for them.

The Expert Patient acknowledged the efforts made by the participants and added:

> *"...there is no point of me saying you've got to do this and that...it's like we're back to square one...unless we both (participants and Expert Patient) agree as to what needs to be done and how to achieve our goals..."* (EP04).

Other participants appeared to be searching for different self-management practices to help them manage their condition on a daily basis. The GEPP was timely and gave them answers and tips they needed.

One participant commented:

> *"...I try to remember putting the drops in, but to be honest I tend to forget them quite often, she (Expert Patient) suggested to put the drops either in the toilet next to my toothbrush so they are there in front of me so I remember or next to my bedside table so I can see them when I am in bed...you see I never thought of that..."* (IG06).

Personal experience with glaucoma was related to participants by the Expert Patients during the intervention. For example, the importance of family member screening as a way of early detection of glaucoma was explained. An Expert Patient commented:

> *"I used to come to the clinic with my mom before she died, and they always told me to get my annual check-up with the opticians...On one occasion the optician told me that my pressures were up and he need to refer me to Moorfields...I knew it then, that's it, I am getting the same thing... so I tell every participant I work with this story so they remember to do the same with their siblings... This is the only way they would know that they have it..."* (EP03).

Another Expert Patient added:

> *"I had to give up driving as a result of glaucoma, which is something I really miss a lot. So I tell every participant that...you know some people are driving for a living and have to give it up. That can be a bit of problem... unless we tell them that they probably wouldn't know..."* (EP01).

A participant who drives a lorry for a living commented:

> *"I knew glaucoma affects your ability to drive...but I didn't know how...as I have perfect vision...I didn't know losing the peripheral vision would stop me from driving..."* (IG11).

5.2.3.2 Maintaining Consistency (Motivation and Behavioral Skills)

To avoid any variations in the intervention delivered by the Expert Patients to different participants, it was vital to cover the main constructs of the IMB model based on the individual needs of participants. Whilst maintaining the focus of improving the knowledge amongst all participants, it was equally important to consider barriers and behaviours that impact concordance. For example, a young educated participant had been diagnosed with glaucoma and had not been keeping his appointments or taking his eye drops regularly given the fast progression of his glaucoma. After a long conversation with one of the Expert Patients, this is what the EP had to say:

> *"...this young gentleman is very knowledgeable and understands his condition very well...the problem is he doesn't believe he has glaucoma...He is only 27 years of age and has no family history of glaucoma and so does not take his eye drops... After a long chat with him, he understands that not taking the eye drops if anything will make the situation worse and he will subsequently pay the ultimate price...I draw a lot on my personal experience with glaucoma and how ignorant I was at the beginning...He listened to me and was like...what you're saying actually make sense..."* (EP01).

I had the chance to speak with this gentleman afterwards and he said the following about the Expert Patient:

> *"...she was very informative and very reasonable...If someone has been through this and telling me at the end of the day they are the one who lost their sight...I think I buy that and listen to what she says...although I don't believe what the doctors are telling me here...but I don't want to go blind either..."* (IG13).

This gentleman found it difficult to accept the reality of his condition and may well subsequently have a surgical procedure to reduce his IOPs before it is too late. The Expert Patient conversation will definitely help him accept the situation and he may well accept having a Trabeculectomy (surgery) if the eye drops continue to be an issue for him. I reflected on this interaction and wrote in my field notes:

> *"I am impressed with the flexibility the Expert Patient has shown and the ability to change some of the beliefs this gentleman was holding toward glaucoma...It was apparent that a lack of knowledge was not an issue...She moved to the next IMB construct which is motivation, she identified that he has poor motivation and confidence...She addressed that and then ensured*

> *he is holding the necessary behavioural skills to achieve concordance"* (Field Note).

Communicating such conversations to the health professionals caring for this participant will alert the Ophthalmologist to the situation who may be able to alter the course of treatment or the direction of treatment all together.

The IMB model provided not only comprehensive guidelines on understanding the issue of concordance; it also ensured a consistent delivery of the intervention and enabled Expert Patients to address barriers to concordance.

5.2.3.3 Re-enforcement of the Expert Patients Teaching and Learning (Sustainability)

The first and second follow ups were an opportunity to reinforce learning acquired from the intervention. Although the findings will be presented in detail in the mixed method section, for clarity I mention that participants were asked to comment on the intervention they received. I took this opportunity to answer their questions and validate the teaching delivered by the Expert Patients. To incorporate feedback into the results I left a section in the questionnaires for participants to comment on the performance of the Expert Patient. Most participants were full of praise and wanted to speak to the Expert Patients again. Many thought some of the tips given worked for them.

The following are a few of the comments made by participants from the Intervention Group on their follow up visit:

> *"...this is a very good idea especially for elderly people who can't find information anywhere else...it could save them their sight knowing how dangerous glaucoma is"* (IG01).

> *"My wife has glaucoma as well...I didn't really know much about glaucoma and I keep asking her as we help each other to put the drops in...So it is useful for everyone to know about their conditions and find someone you*

> *can speak to...I wish my wife was here. She could have appreciated this session a lot"* (IG02).

> *"I think this is a very good idea. Sometimes I feel like talking to someone who is experienced and been through what I am going through now...and to find out how other people are coping with this condition... The lady (Expert Patient) is very knowledgeable and helpful"* (IG03).

Participant IG22 who was accompanied by her son who is also a glaucoma sufferer commented:

> *"this is a great idea, we both have been patients for years and we never had the opportunity to sit with someone and spend the time as we did today talking about it (COAG) and how it could affect our lives...For example, we never understood why they do the visual field every time we come to the clinic or what the eye pressure reading should be...Thank you for the opportunity and for her (Expert Patient) efforts"* (IG22).

> *"...I hated the visual field test...I never knew why they were doing it...I call it the torture chamber...but now (after the session) it all makes sense and I asked them to see the results and then when they compared it to what it was last time...you know it is really reassuring to know that things are not getting any worse..."* (IG19).

> *"You know I never knew what my pressure readings were...but after this session I understand what the pressure means and what it should be... Now they told me the pressures are down to 16 and 12 which is normal...It is nice to know that I am doing a good job and the drops are working for me..."* (IG23).

It is evident from these comments that participants often wanted to know and learn how to assume greater responsibility about how to manage their condition. The Expert Patients gave them a starting point and a platform to build on.

5.2.4 Recruitment of the Control Group

The control group findings are presented in comparison with those of the intervention group in the mixed method section below. For clarity 25 participants were recruited in the control group of which 10 participants were interviewed.

5.3 Findings From the Mixed Methods Evaluation

Obtaining baseline data was an essential step to determine how knowledgeable and motivated these two groups were post intervention. This section serves the purpose of comparative evaluation between each group before and after intervention and between groups comparison. It presents the three time series of the quantitative findings from participant groups including: Expert Patient Group, Intervention Group and Control Group. Simultaneously findings from the interviews conducted with selected participants of the groups will also be presented.

5.3.1 Expert Patients Group

Four patients who met the inclusion criteria and showed commitment and enthusiasm to participating in this research were recruited. The following sections describe their demographic data and the results.

5.3.1.1 Demographic Data

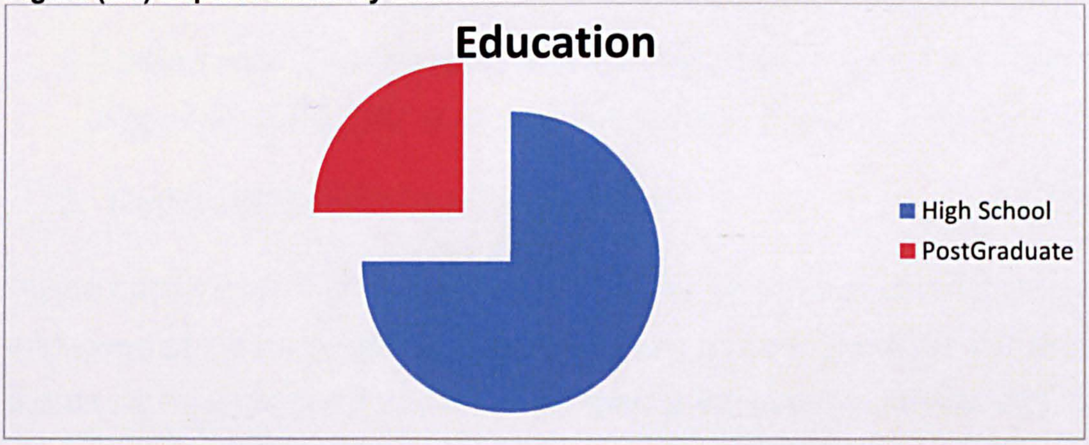
Three of the participants were of white ethnicity and one was of black ethnicity as illustrated in figure (5.2) below.

Figure (5.2): Expert Patient by Ethnicity

Although I had hoped to recruit an Expert Patient of Asian ethnicity so as to reflect the diversity of the community served in this research, it was not possible to find a participant that meet the inclusion criteria.

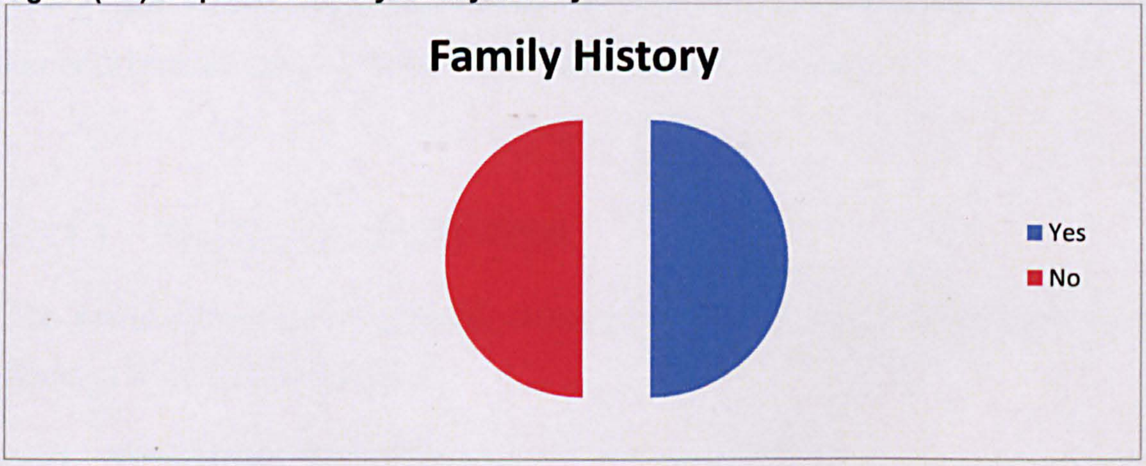
Three out of the four have a high school qualification whilst the fourth has a postgraduate qualification and long experience in coaching young entrepreneurs as illustrated below in figure (5.3).

Figure (5.3) Expert Patient by Education



Half of the Expert Patients have a family history of glaucoma as shown in figure (5.4).

Figure (5.4): Expert Patient by Family History



5.3.1.2 Pre-Intervention Findings:

The baseline data for the Expert Patients Group were obtained directly after recruitment and prior to the training provided.

1. **Knowledge (Appendix 3)**

Although the Expert Patients were considerably knowledgeable and knew the ins and outs of the clinics, it was important to assess the impact of the training/intervention as well as their learning gained through this research. Therefore, their level of knowledge was assessed on baseline before getting involved in this study. The mean on baseline was (23.25) and the SD was (2.5).

An Expert Patient commented:

> *"I think it was important to receive this training as I discovered that there are things I don't know about glaucoma even after 20 years of having it"* (EP04).

2. **Motivation/Satisfaction (Appendix 4)**

As the Expert Patient group has been attending the clinic for over 10 years, their ideas and views of the treatment received have been formed. Therefore it is expected there will be minimal change if any when comparing the baseline results with the follow up results. The mean was (35.5) whilst the SD was (8.347).

3. **Adherence (Appendix 5)**

The Expert Patient participants were not using any eye drops regimens as they had surgical procedures; therefore it was not possible to measure for adherence.

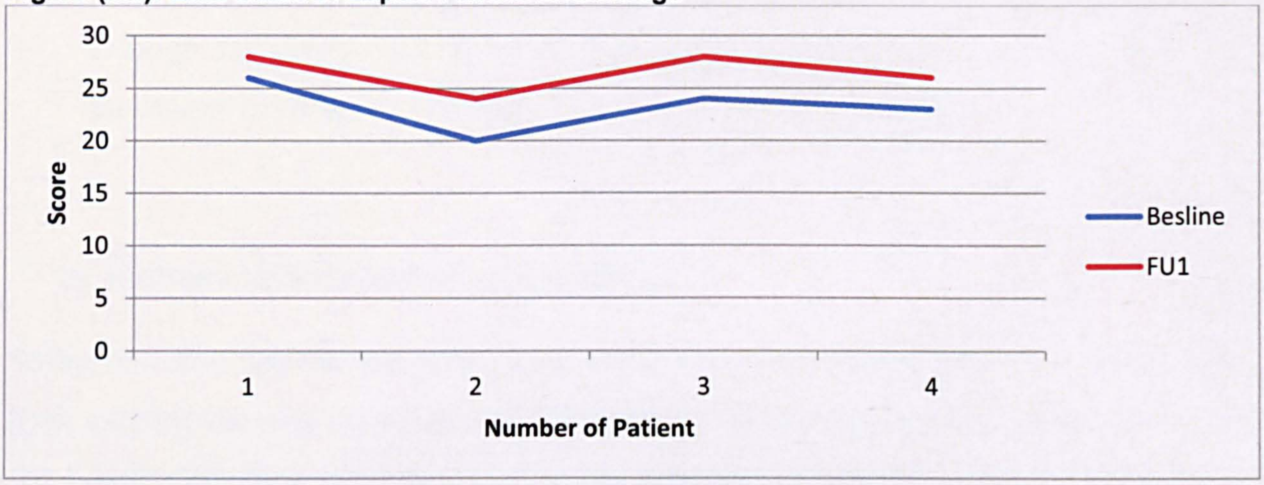
5.3.1.3 Post-Intervention Findings

The same outcomes were measured again on the completion of the study and the findings were as the following:

1. **Knowledge (Appendix 3)**

A follow up assessment was conducted on completion of the intervention. As expected the results revealed a small improvement, the mean was (23.25 on baseline and 26.5 on follow up). The SD was (2.5 on baseline and 1.91485 on follow up). Using Wilcoxon Signed Ranks Test at 0.05 probability showed a p-value of (0.066) which is not statistically significant. The following figure (5.5) demonstrates this change.

Figure (5.5): Line Chart of Expert Patient Knowledge



The above line chart represents the small change in Expert Patients' knowledge. The blue line represents the level of knowledge on baseline whilst the red line represents the knowledge after the completion of the intervention. All Expert Patients' knowledge has marginally improved.

Expert Patient evaluation of the knowledge gained from the GEPP was also measured through semi-structured interviews and they commented:

> *"I learned a lot from this project… lots of information at the beginning of the project and I think more importantly the life experience of patients and how they coped and managed their glaucoma…"* (EP01).

> *"Having been diagnosed a few years ago I found that the training and discussion were helpful for me to understand the problem of glaucoma"* (EP02).

> *"…I knew a bit before about glaucoma…and learned a lot during this project…It is great to know the problem with your eyes and that I am not going blind like my mom, as I always thought"* (EP03).

When asked whether the training and the information gained were useful, an Expert Patient suggested:

> *"The training was very good but in my opinion was not sufficient to get enough day-to-day problems sorted such as informing the DVLA and insurance company..."* (EP02).

2. **Motivation/Satisfaction (Appendix 4)**

Motivation and satisfaction of the Expert Patients comprised of two main parts. First their satisfaction with the treatment and experience with the running of the clinics and the health care they received in the clinic. This was measured using the satisfaction questionnaire (refer to the questionnaire in the appendix 4) by comparing their baseline responses with those at the end of the study. The results were analysed using SPSS 18 software and showed the following: The mean was (35.5 on baseline and 35.5 on follow up) whilst the SD was (8.347 on baseline and 8.34666 on follow up) and expectedly the p-value was 1.000 using the Wilcoxon Signed Ranks Test. This demonstrated no significant change.

Secondly, Expert Patients were asked in an interview to comment on their satisfaction and involvement and how motivated they felt during this project. The following are comments made by the Expert Patients:

> *"I think our commitment to seeing this project through was an indication of the belief we hold that this is really a worthwhile project and does make a difference..."* (EP01).

> *"...I really enjoyed my time during this project...coming to the clinic where I always received treatment and being part of the team and to make other people's experience a better one was very encouraging...You know coming here and chatting to B.H (clinic manager) and nurses and doctors was really nice...It makes you see things from a different perspective..."* (EP03).

> *"...unfortunately I was only able to attend patients in Upney Lane which really has very limited space and is quite claustrophobic at times...I only saw three patients although I was hoping to see more...It was really brilliant..."* (EP04).

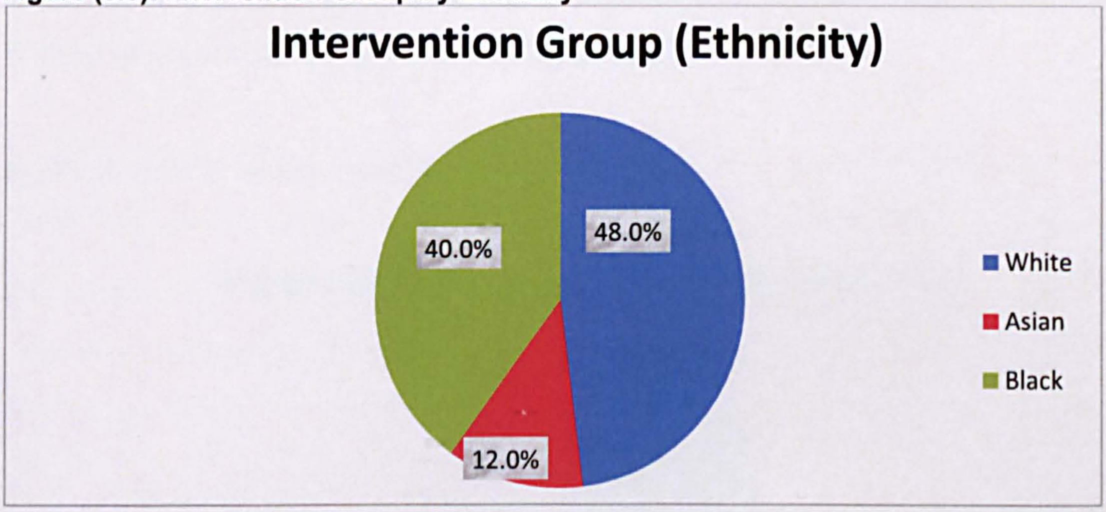
5.3.2 The Intervention Group

The intervention group included 25 newly diagnosed patients attending the clinic within the first two years of being diagnosed. The participants were randomly chosen once they met the inclusion criteria and completed the consent form.

5.3.2.1 Demographic Data

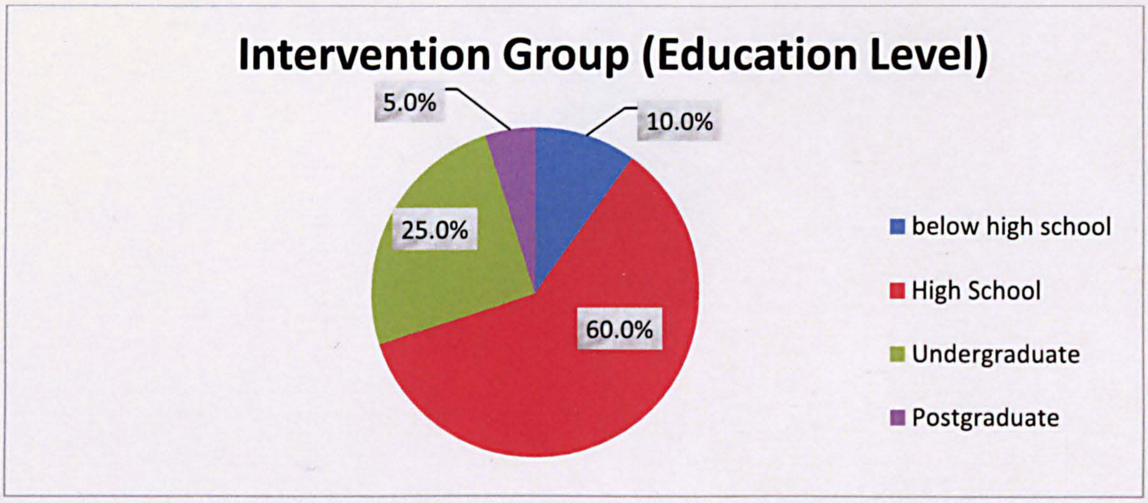
Whilst maintaining the representation of the sample, all efforts were made to recruit a sample that reflects the demography of the community in which this study was conducted. Of those recruited, 48% were of white origin, 40% were of black origin and 12% of Asian origin as illustrated in figure (5.6) below.

Figure (5.6): Intervention Group by Ethnicity



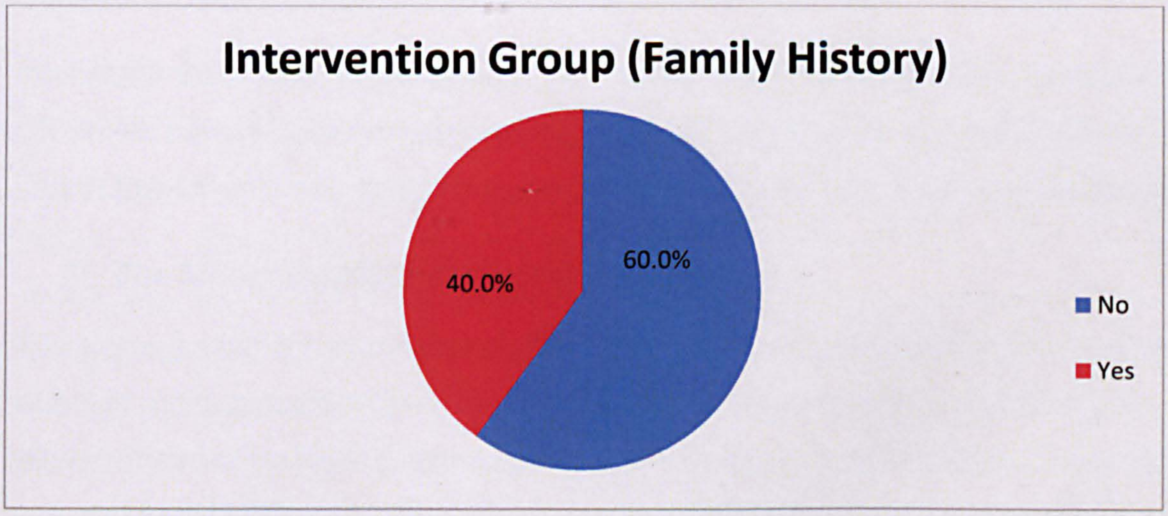
Previous studies have linked poor concordance to patients with low educational accomplishment. The following figure (5.7) illustrates the level of education amongst participants in this group.

Figure (5.7): Intervention Group by Education



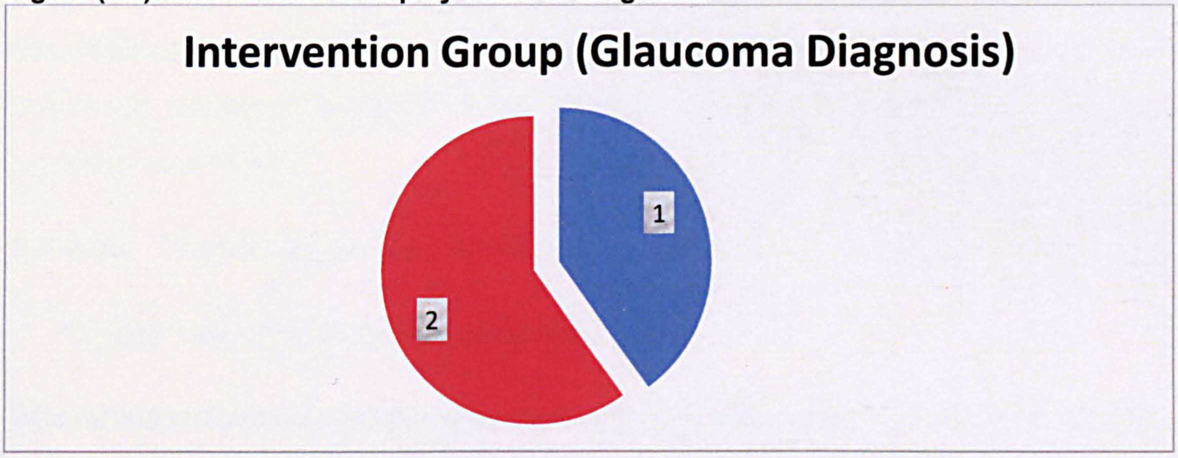
Family history is considered a primary motive for the general public to seek medical attention and attend screening tests. Out of the 25 participants 40% have a family history of glaucoma as illustrated in figure (5.8).

Figure (5.8): Intervention Group by Family History



As mentioned earlier this group of participants has been diagnosed with COAG within the last two years. Of those 40% were in the first year of diagnosis and rest of the group were in their second year of life with COAG as illustrated in the following figure (5.9).

Figure (5.9): Intervention Group by Years of Diagnosis



5.3.2.2 Pre-Intervention Findings

1. Knowledge (Appendix 3)

One of the outcomes to assess the impact of this intervention was the level of knowledge which has been assessed prior to receiving the intervention using a true and false validated questionnaire. On Baseline the mean was (20.40) and SD was (3.500) which will be compared to findings from first and second follow up in a later section.

Interviews were only conducted as part of the evaluation after the intervention was delivered, however, when approaching potential participants and inviting them to take part in this study, the majority of participants showed great interest in the study.

2. The Motivation/Satisfaction (Appendix 4)

The second outcome measured in this study was the participants' level of satisfaction with five main aspects of their treatment. This outcome includes their satisfaction with effectiveness of treatment, side effects of eye drops, eye appearance, convenience of use and satisfaction with ease of administration. A validated scale questionnaire was used and rating was given by each patient. The higher the score the more satisfied they were. The mean on baseline was (54.6) and SD was (7.85812) which will be compared to the findings from first follow up and second follow up.

3. Adherence and Concordance (Appendix 5)

To reflect whether improvement in knowledge will subsequently lead to improvement in the concordance amongst participants, I examined the level of adherence to the eye drops used by asking participants how many times they missed their eye drops over the last four weeks. One may question the reliability of self-report in the tool used. Here the result serves as a guide rather than an accurate measurement. The mean on baseline was (1.8).

5.3.2.3 Post-Intervention Findings

1. The Learning Process (Knowledge)

One of the outcomes measured to assess the effectiveness of this study, was the level of knowledge assessed prior to receiving the intervention and on 1st follow up and 2nd follow up using a true and false validated questionnaire (Hoevenaars et al, 2006).

***Comparing the knowledge on baseline with the first follow up.**

The result showed a statistically significant improvement on the level of knowledge of participants when compared to baseline results (mean 20.40, SD 3.500) with those of the 1st follow up (mean 23.28, SD 2.55799) and a *p-value* of (0.000) using *Wilcoxon Signed Ranks Test.*

***Comparing the knowledge on first follow up with the second follow up.**

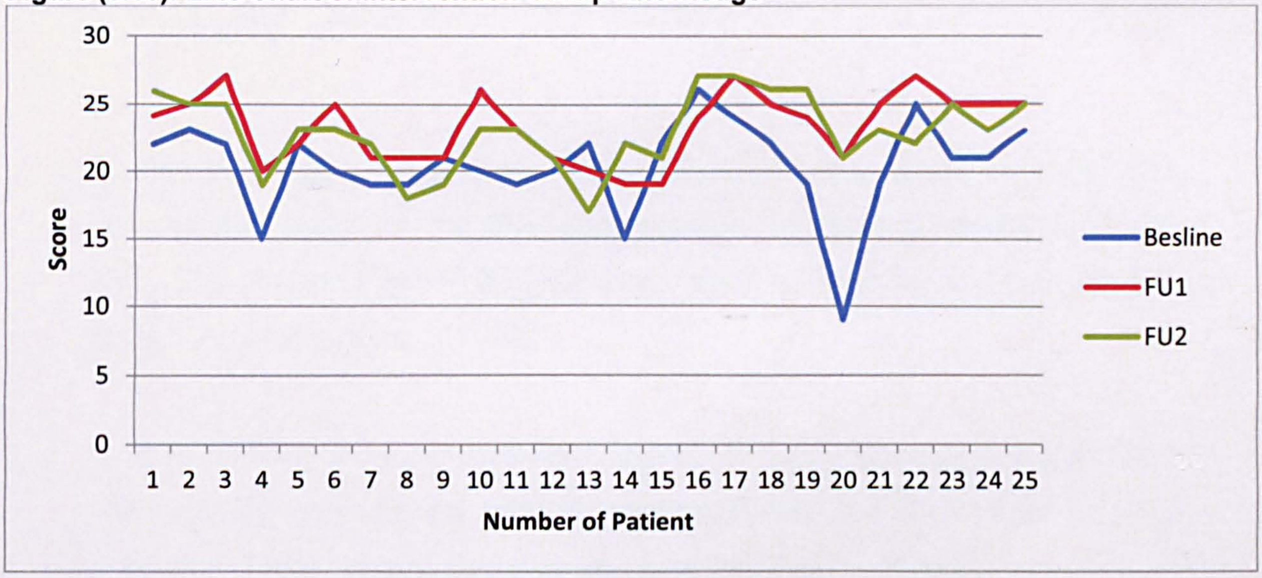
To assess the sustainability of this intervention another comparison between the first follow up and the second follow up on the level of knowledge was undertaken. The results were not disappointing, as participants seem to retain the knowledge they have gained during this intervention. There was no further improvement, as the results were similar as shown in the mean and SD values. With first follow up results (mean 23.28, SD 2.55799) and the second follow up (mean 22.88, SD 2.75862) and a *p-value* <0.005 using the *Wilcoxon Signed Rank Test* which reflects a significant result in retention of knowledge.

***Comparing the knowledge on three data sets (Baseline, first and second follow up).**

For a more comprehensive test of the sustainability of this gain in knowledge, further test that compares the results on baseline with results from the first follow up and second follow up using *Friedman Test* was conducted. The Mean for this comparison was (20.40 on baseline, 23.28 on first follow up and 22.88 on second follow up) whilst the SD was (3.500, 2.55799 and 2.75862) respectively. The p-value was calculated at 0.000 using Friedman Test and Kendall's W Test.

For a better illustration of this comparison, the following figure (5.10) provides an indication of the knowledge gain on each episode:

Figure (5.10): Line Chart of Intervention Group Knowledge



(FU=Follow Up)

As can be seen from the above chart there was an obvious improvement on participants' level of knowledge quantitatively. Interviews conducted reflected similar trends.

On the terminology and jargon used in the treatment of glaucoma for example, participants said:

> *"...You know some of the terms and words they use...I didn't really understand everything they told me...but now that someone explained it to me it makes more sense..."* (IG03).

> *"...as I said I knew a bit about glaucoma, but there is always more for you to learn...I learned useful things from her (Expert Patient)..."* (IG02).

When asked what difference this research made for them, participants commented:

> *"...You could say I am more confident now and more familiar with all the stuff they say, how to use the drops, where to get a repeat prescription and all that...You know it puts your mind at rest"* (IG05).

> *"I think it helped me in many ways...You know the more you know it puts your mind at rest instead of keep worrying about it and not knowing what to do..."* (IG07).

> *"...they do explain things here, but for example, I didn't know that I have to use my eye drops all the time and to get a repeat prescription from the GP...She (Expert Patient) told me that I have to do that...but how would I know...no one told me"* (IG09).

> *"...It is difficult for a non-medical person to understand the words they use...though she (Expert Patient) explained this and that...It is good to understand what is going on with my eyes and stuff..."* (IG10).

2. The Motivation/Satisfaction (Appendix 4)

The second outcome measured in this study was the participants' level of satisfaction with five main aspects of their treatment. This outcome includes their satisfaction with effectiveness of treatment, side effects of eye drops, eye appearance, convenience of use and satisfaction with ease of administration. A validated scale questionnaire (Day et al, 2006) was used and rating was given by each participant. The higher the score the more satisfied they were.

***Comparing the level of satisfaction on baseline with the first follow up.**

In order to reflect any improvement on satisfaction, a comparison of the baseline results was made with first follow up. The results were encouraging as the baseline results were (mean 54.6, SD 7.85812) as compared to 1st follow up (mean 57.8, SD 9.16515), using *Wilcoxon Signed Ranks Test* which showed a *p-value* 0.133. Although there was an improvement in the level of satisfaction, the improvement was relatively small to make any statistical difference.

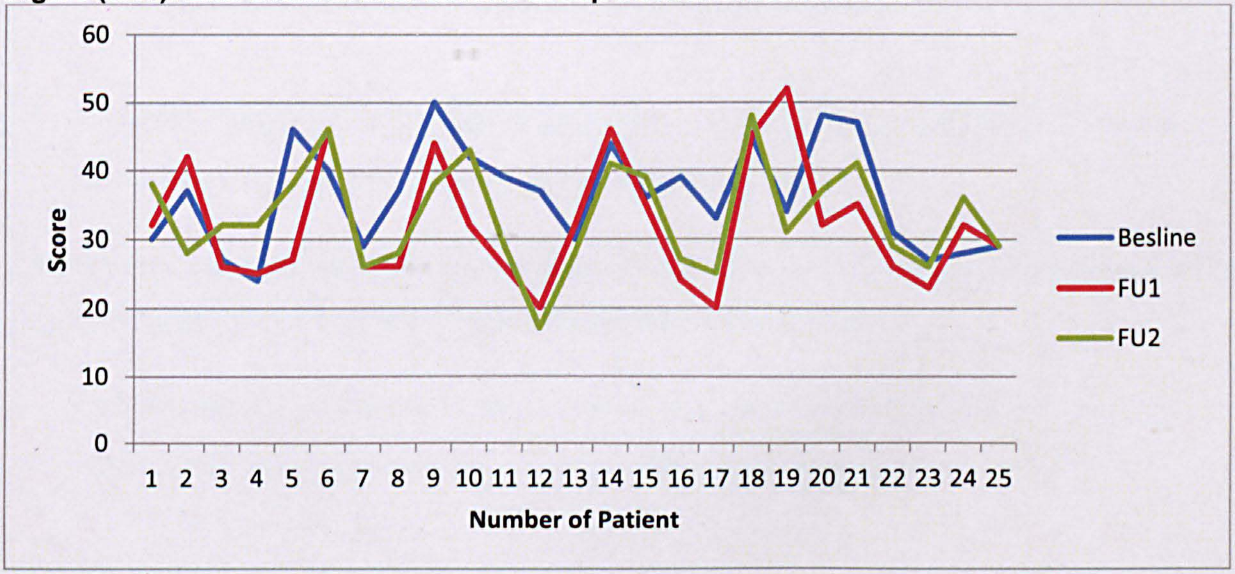
*Comparing the level of satisfaction on first follow up with the second follow up.

To examine whether this small improvement was sustainable over time, a further comparison was made between first follow up and second follow up. The results revealed relatively similar means (1st follow up 57.8, 2nd follow up 56.72) and the SD (1st follow up 9.19515, 2nd follow up 7.46949) and a *p-value* 0.078 using *Wilcoxon Signed Ranks Test*, which is not significant indicating that satisfaction remained pretty stable over time.

*Comparing the satisfaction on three times (Baseline, first follow up and second follow up).

This comparison provided an overall perspective of the changes of participants' level of satisfaction when comparing the three level of satisfaction using *Friedman Test* which revealed a *mean* of (Baseline 1.8, 1st follow up 1.94, 2nd follow up 2.26). Although there was a small improvement as reflected by the mean results, the improvement was relatively small and was reflected in the *p-value* 0.224. Refer to chart (5.11).

Figure (5.11): Line Chart of Intervention Group Motivation/Satisfaction



Participants' satisfaction with the above mentioned five aspects of their treatment were also measured in semi-structured interviews and responses were as following:

a. Effectiveness of Treatment

When asked how effective they thought their eye drops were in controlling their glaucoma, responses were varied. Some participants based their judgment on the side effects of the eye drops and commented:

> *"...I am not sure these eye drops are doing me any good or agreeing with my eyes...ever since I started using them my eyes, as you can see, are very red and gritty..."* (IG07).

> *"...they said the drops will solve the problem...but look how red and crusty my eyes are..."* (IG08).

> *"I am still doing the drops but I am not sure if it is doing much to be honest...as they make my eyes very gritty crusty and red especially in the morning which is something I never had before"* (IG02).

> *"I didn't have any symptoms at all until I started using the eye drops... That's why I was not very convinced at the beginning"* (IG01).

Other participants based their responses on how effective the drops were in controlling the IOPs and glaucoma as indicated by following responses:

> *"Every time I come here they check the pressures and say Mr X your pressures today are normal...I guess they are doing the job..."* (IG06).

> *"...I am lucky they caught it early so I have not suffered much damage...and it seems the drops are doing the trick"* (IG10).

b. Side Effects of Eye Drops

As one of the major barriers of glaucoma is concordance, the side effects of eye drops prescribed remained a challenge for participants; although now they understand the need for these drops.

> *"...knowing the drops are working for you...and when I come to the clinic and they check my pressures and say your pressures are okay and all good...I guess it is worth it at the end..."* (IG04).

Though not all participants reported having side effects, some participants were entirely not bothered with the side effects caused by the drops as one commented:

> *"...They never caused me any problem really...I just do what I am told...I put the drops in every night and that's it..."* (IG09).

c. Eye Appearance

Eye appearance was consistently expressed as one of the main themes in these interviews. Even some of the Expert Patients expressed concerns on the appearance of their eyes. This was particularly a concern amongst the younger participants who were always asked by colleagues or family why their eyes were always red as expressed by this participant:

> *"...As you can see my eyes are always gritty and red. You know my colleagues at work keep asking what's wrong with your eyes? Or are you alright? It is really annoying"* (IG06).

For other participants, understanding the necessity of using the eye drops was a motivation and an encouragement for them to overcome these concerns as one commented:

> *"Whenever I look in the mirror and see my eyes red it upsets me...but once you understand these drops actually are saving your sight it makes it easier to accept it and you get on with your life..."* (IG04).

d. Convenience of Use

Participants' responses also varied based on the treatment regimen followed. For some participants one eye drop to be used every night was enough to control the IOP and so it was more convenient for them in comparison with other participants who have to use additional eye drop(s) two or three times a day to control the pressure.

IG01 commented:

> *"...They started me on G.Xalatan to use every night which was okay...but then she said the pressure was still high...so she gave another drop to use twice a day which stings when I put it in...and you know I work and sometimes I leave in the morning and forget to put the drop in..."* (IG01).

> *"...It doesn't really bother me...Every night I put the drop in and that's it really...and I am quite good I don't miss them at all...My wife also reminds me 'did you do your drops'..."* (IG05).

> *"...I travel a lot... and before I was not really that good I always forget them...but when I came here they told me your pressures are still high and stuff... then she (Expert Patient) told me you can keep them in your bag so even if you travel or don't come home you have them with you... which so far is working...but you see when I run out of them that's the problem"* (IG14).

e. Ease of Administration

As explained earlier the majority of COAG patients are elderly and have other health conditions like arthritis. Mastering the skill of dropping drops can be challenging. As drop instillation was the main aspect of this intervention, responses were generally positive. Expert Patients explained to all participants the technique of instilling eye drops and asked them to demonstrate using the drops. The responses were generally encouraging as indicated in the following narrative:

> *"...At the beginning it was difficult to get the drop exactly in the eye...Sometimes it drops on my cheek or eyelid...but I was doing it blindly...She told me to look in the mirror which really made it easier...I am much better now...at least the bottle last me for all the month...before they always run out and not lasted long enough..."* (IG14).

> *"She gave me this little dropper which I attach to the bottle and it is much easier to use them now..."* (IG09).

3. Adherence and Concordance (Appendix 5)

To reflect whether improvement in knowledge will subsequently lead to improvement in concordance amongst the participants, I examined the level of adherence to the eye drops used by asking participants how many times they missed their eye drops over the last four weeks. One may question the reliability of self-report in the tool used, but here the result will serve as a guide reflecting a semblance of adherence and concordance.

***Comparing the level of adherence on baseline with first follow up.**

This comparison revealed a 1.8 *mean* on baseline and 2.0 on 1st follow up using the *Wilcoxon Signed Ranks Test*, and a *p-value* 0.059. Which showed some improvement but again not large enough to be deemed significant.

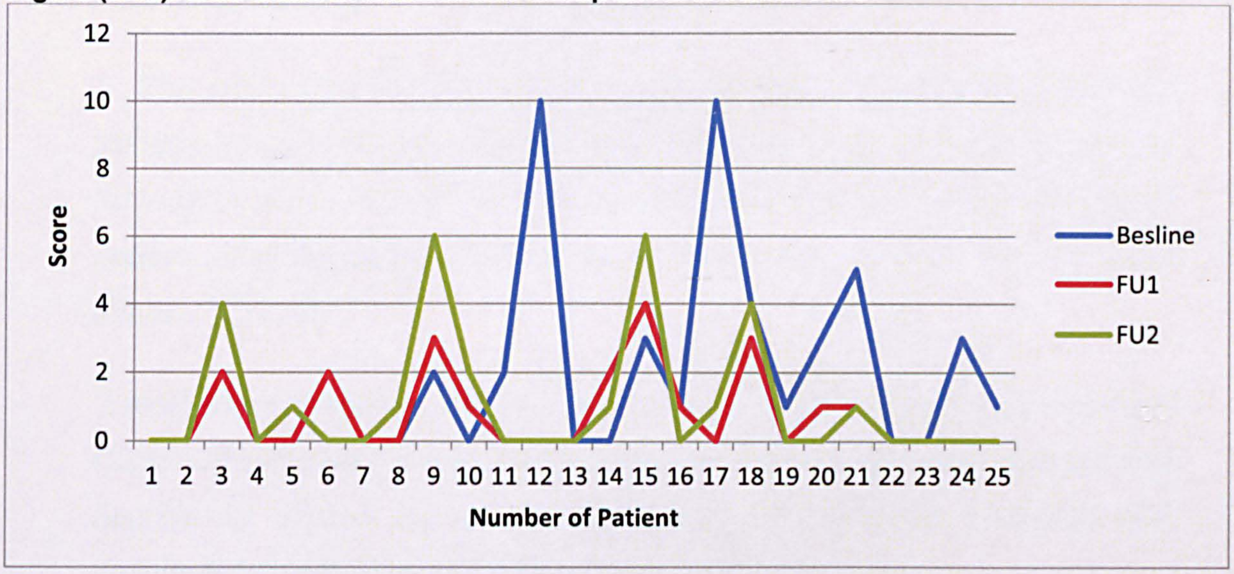
***Comparing adherence on first follow with second follow up.**

Again this comparison has provided similar results to the previous comparison, with a relatively small improvement that is not statistically significant. The *Wilcoxon Signed Ranks Test* showed a *Mean* of 2.0 on 1st follow up and 2.2 on 2nd follow up respectively and a *p-value* of 0.208 which again is not statistically significant.

***Comparing the adherence level on baseline and first follow up and second follow up.**

A more comprehensive look at the trend over the three episodes was made by this comparison and results showed a *Mean* (1.8 baseline, 2.0 1st follow up, 2.2 on 2nd follow up) and a *p-value* 0.189 using the *Friedman Test.* The following figure (5.12) provides a better illustration over the entire period.

Figure (5.12): Line Chart of Intervention Group Level of Adherence



The above chart shows a small overall improvement in terms of concordance, however, individual participants who had major issues with either accepting the condition or how to use eye drops or in fact the necessity of these eye drops, is where the GEPP has made the difference. Given the subjectivity of the self-report questionnaire used and the relatively small sample size the t-test results were not expected to be of high significance. Therefore, semi-structured interviews were conducted to give an insightful evaluation of the difference the GEPP made.

The participant, who was presented as a case study in section (5.1.3.3), might be remembered as a participant that missed her appointments twice and was not interested in attending her appointments. She commented:

> *"I am really glad I was given this opportunity…She (Expert Patient) was so lovely and helpful…If anything I feel much happier coming to the clinic and less guilty of not doing the right thing you know…and most of all I don't keep*

> *worrying that I am going to go blind and who is going to look after me and you know these thoughts are no longer there..."* (IG14).

Other participants thought of the GEPP as:

> *"It really helped me accept things...She (Expert Patient) was very informative and kind...listening to her just made me think 'maybe she has got a point you know and I should do something about it'...I learned a lot from her..."* (IG15).

> *"...She was very informative and very reasonable...If someone has been through this and telling me at the end of the day they are the one who lost their sight...I think I buy that and listen to what she said...although I don't believe what the doctors are telling me here...but I don't want to go blind either..."* (IG13).

> *"I really dread coming to the clinic...but since I started coming to "Loxford Clinic" with the staff here...and this project...I feel a lot more relaxed and happier to attend the clinic...Personally I feel more confident and knowledgeable than before I would say..."* (IG16).

Other participants thought the idea of having a patient sharing their experience and knowledge with another patient was:

> *"...I like the idea that this project is run by patients...just made me think why someone would waste their time explaining things to me unless it is worth listening to..."* (IG19).

Other participants were less appreciative of the GEPP and thought efforts should be focused on staffing issues and reducing waiting times.

> *"...She was okay...you know she explained things to me...but I think the problem is with how this clinic is run...It is always busy and you probably have to spend three hours before you get to be seen"* (IG21).

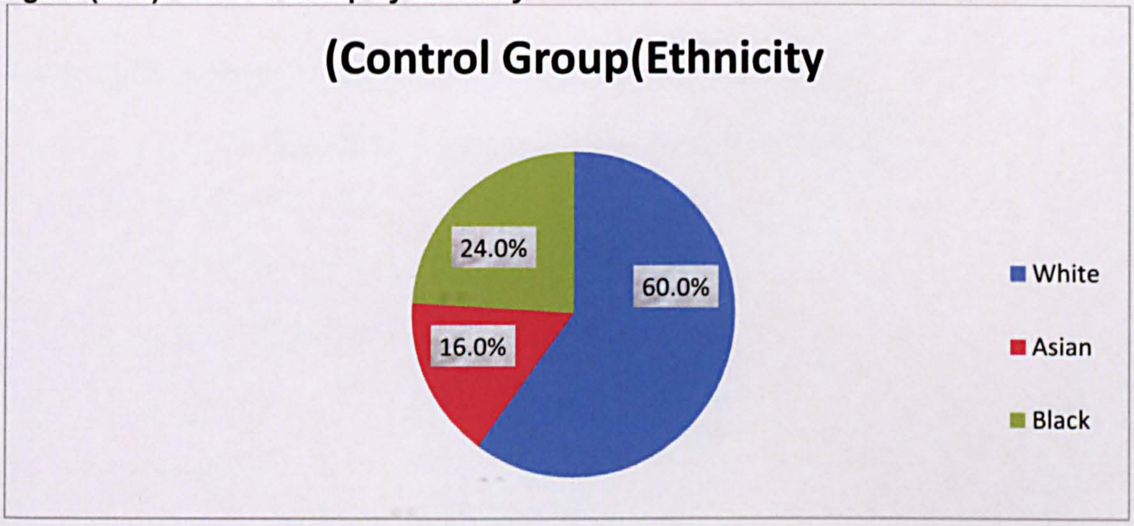
5.3.3 Control Group

This is a group of participants who were recruited non-contemporaneously from the same clinic on the completion of the intervention evaluation of the intervention group. 25 newly diagnosed patients in their first 2 years of life with glaucoma were purposefully sampled to carefully match the demographics of the intervention group.

5.3.3.1 Demographic Data

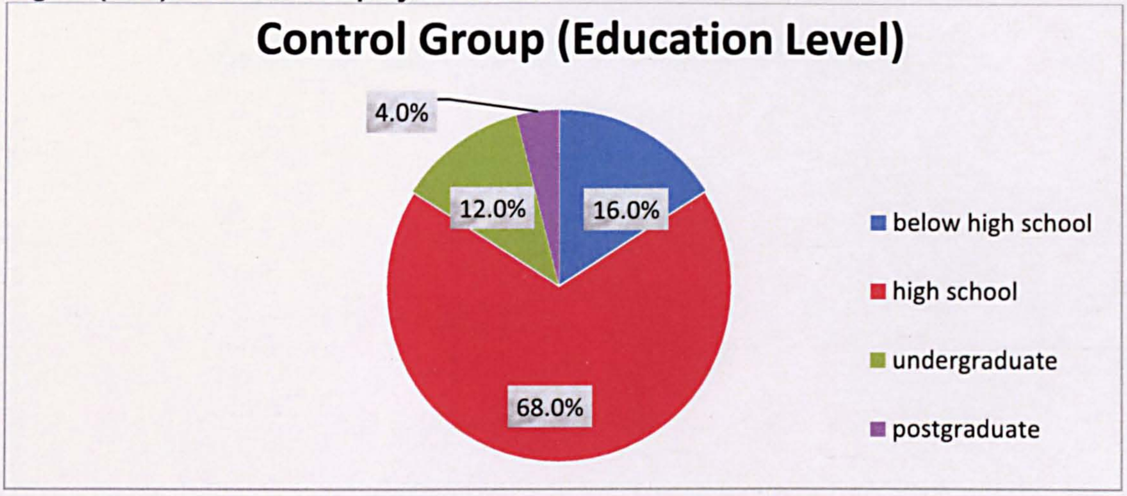
This group comprised 25 participants from three ethnic backgrounds. Of which 60% were of white ethnic background as opposed to 48% in the intervention group, 24% of black ethnic origin as compared to 40% in the intervention group and 16% of Asian origin in comparison to 12% of the intervention group, as illustrated in the following figure (5.13).

Figure (5.13): Control Group by Ethnicity



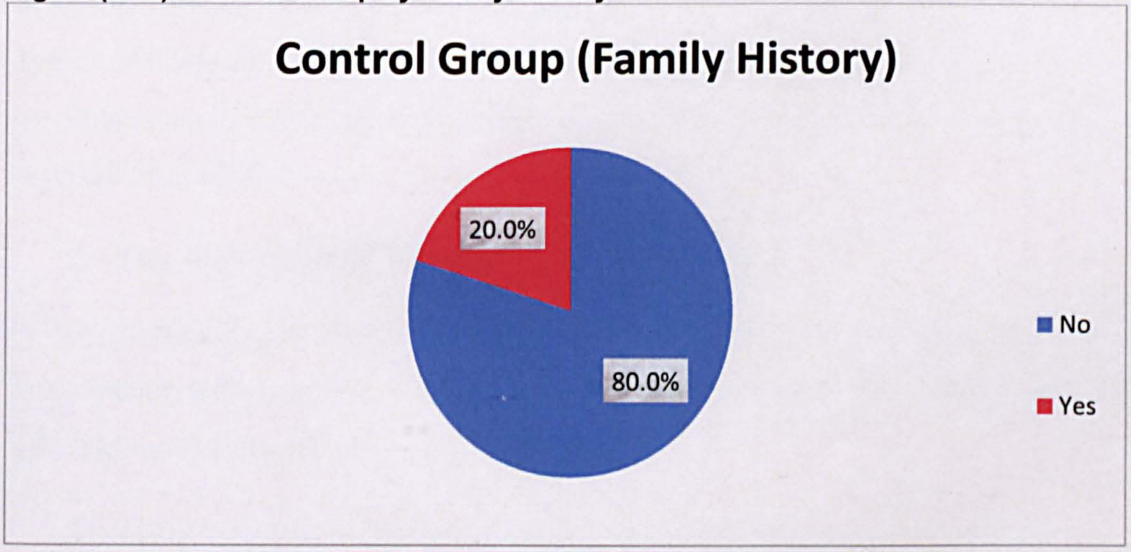
The education level was similar to the intervention group as illustrated in figure (5.14). 16% of control group were below high school compared to 10% in the intervention. 68% of control group have a high school qualification in comparison to 60% in the intervention group. 12% of the control group have an undergraduate qualification as compared to 25% in the intervention group. Both groups have 5% of participants with a postgraduate education level.

Figure (5.14): Control Group by Education



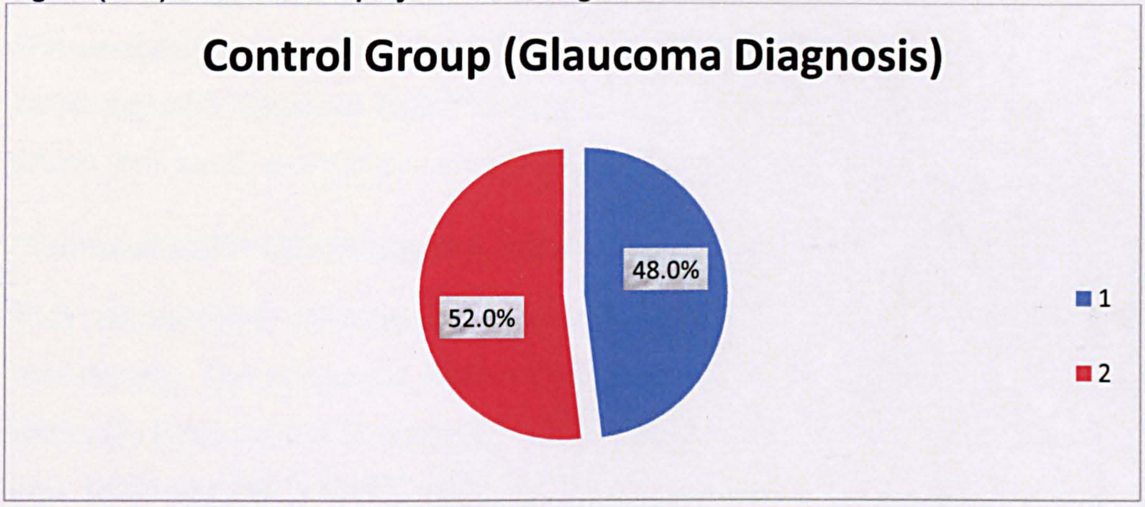
The following figure (5.15) shows that only one fifth of the participants in this group have a family history of glaucoma as opposed to two fifths in the intervention group.

Figure (5.15): Control Group by Family History



Almost half of the participants in this group were in their first year of being diagnosed whilst the other half were in their second year of diagnosis is explained in the following figure (5.16).

Figure (5.16): Control Group by Years of Diagnosis



5.3.3.2 Pre-Intervention Findings

1. Knowledge (Appendix 3)

When a glaucoma patient attends the outpatient clinic there are naturally occurring learning opportunities in which a patient will presumably gain knowledge. This is a result of frequent attendances in the clinic and conversations held with professionals and other sources of learning in life. On baseline the mean of Knowledge was (19.52) and *SD* (3.94884).

2. The Motivation/Satisfaction (Appendix 4)

When conducting a similar assessment of the Control group's level of motivation and satisfaction with the five main aspects of their treatment. The *Mean* on baseline was (37.04), whilst the *SD* was (10.74508).

3. Adherence and Concordance (Appendix 5)

Adherence to treatment regimen was also assessed in the same way. The Mean on baseline was (2.04) and the SD was (2.590).

5.3.3.3 Post-Intervention Findings

1. Knowledge (Appendix 3)

To assess whether the improved knowledge in the intervention group was a result of the intervention delivered or was a naturally occurring event. The level of knowledge amongst this group of patients was compared to the control group. The same set of knowledge questionnaire (Hoevenaars et al, 2006) used with the intervention group on three different occasion (prior to recruitment, first follow up and second follow up) which took up to six months, were used with the control group.

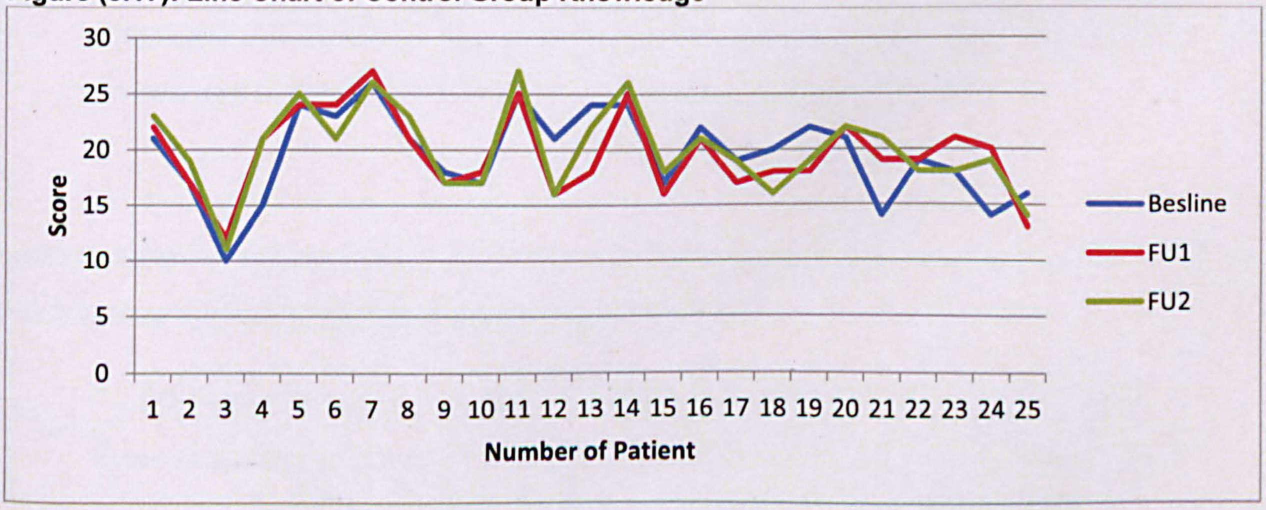
*Comparing the knowledge on baseline with the first follow up.

This comparison examined knowledge gained during the first three months of recruitment. There was no intervention apart from the routine care received in the clinic. On baseline the *Mean* was 19.52 and *SD* 3.94884, whilst on first follow up *Mean* was 19.64 and *SD* 3.70675, which is almost equal resembling no improvement. Using *Wilcoxon Signed Ranks Test, p-value* was 0.88. When comparing the first follow-up with the second follow up, there was no improvement shown with *p-value* of 0.143.

*Comparing the knowledge on three data sets (Baseline, first follow up and second follow up).

An overall comparison of the three episodes has revealed very similar results (Mean: 19.52 on baseline, 19.64 on 1st follow up and 19.96 on 2nd follow up) and (SD: 3.94884 on baseline, 3.70675 on 1st follow and 3.86738 on 2nd follow up). These values represent very little improvement which is reflected in the p-value of 0.635 using the Friedman Test. In comparison with the p-value of the intervention group using the same test which was 0.000, clearly it can be seen there is a difference. The following figure (5.17) represents the learning curve of the control group over the six months of involvement in this research.

Figure (5.17): Line Chart of Control Group Knowledge



This chart shows a small naturally occurring improvement in the level of knowledge amongst participants in this group. Semi-structured interviews were conducted to elaborate findings.

The majority of participants whilst valuing the importance of information they received whilst attending the clinic, highlighted the frustration, fear and apprehension that is associated with a lack of information as presented in the following narrative:

> *"...It is quite difficult for me to understand things because I am not sure if I have glaucoma or not and they are not clear with me. I asked them many times, if I don't have it then there must be something else that makes my vision so blurry...I lost sight in my right eye... I am really frightened what could happen to me if I lose the other eye"* (CG05).

> *"...I don't really know much about glaucoma and I am not sure if I have it or not..."* (CG06).

> *"...They explain things to you only if you ask them...You see my knowledge is very limited...They are the ones who have wide experience with glaucoma...They are the ones who should be telling us more about glaucoma rather than we asking stupid questions..."* (CG07).

> *"...I don't really understand what glaucoma is or how it is being managed...All what I know is that I have high pressures in my eyes and I should put these drops in my eyes to bring it down..."* (CG08).

When asked how important knowledge was for them and whether they wanted to know more, they rated knowledge highly and commented:

> *"...Dad went completely blind because of glaucoma...so I want to know if there is anything I can do to stop me from going blind...I know I am lonely I have not got any children or anyone to look after me..."* (CG05).

> *"I would like to know more…It is my body and I would like to know what they are doing with it"* (CG08).

> *"…I want to know more…I really do…because I am always scared of the thought of going blind and I am still young and have children and the thought of me going blind and not to be able to see my kids and my grandkids in the future frightens me…I am always worried about my eyes…"* (CG07).

> *"I think it is necessary to learn more about it…Personally I would like to know why I am taking these drops and what I am taking them for and for how long and the consequences of and the risk associated with it"* (CG03).

When asked what source of information they were likely to use if they did not receive the information they wanted from the clinic, they commented:

> *"…I joined the IGA (International Glaucoma Association) and read on their website which has a lot of information…but I don't understand everything…"* (CG03).

> *"…I found a leaflet in the waiting area and took it home and read it at home…"* (CG10).

> *"…I just go online and google it and read about it…but sometimes it is very confusing and scary the stories you read online…"* (CG07).

However, some participants were happy with the amount of information that was given and thought that was enough to help them manage their condition as commented below:

> *"It was explained to me and they told me what I need to do and how to stop the glaucoma...with all fairness...they do explain things to me and try to help me with my treatment"* (CG01).

> *"I am quite satisfied with what they explained to me... I am the type of man I just do what I am told...I do the drops...come to my appointment and just get on with my life...They are the experts and I think they know what they are doing..."* (CG02).

2. The Motivation/Satisfaction (Appendix 4)

When conducting a similar comparison on control group participant's satisfaction with the five main aspects of their treatment, the results were as the following.

*Comparing the level of satisfaction on baseline with the first follow up.

The *Mean* for baseline was 37.04 and for first follow up 38.76, whilst the *SD* was 10.74508 and 9.84158 respectively. Applying *Wilcoxon Signed Ranks Test* has revealed a *p-value* of 0.414, which represents no substantial improvement.

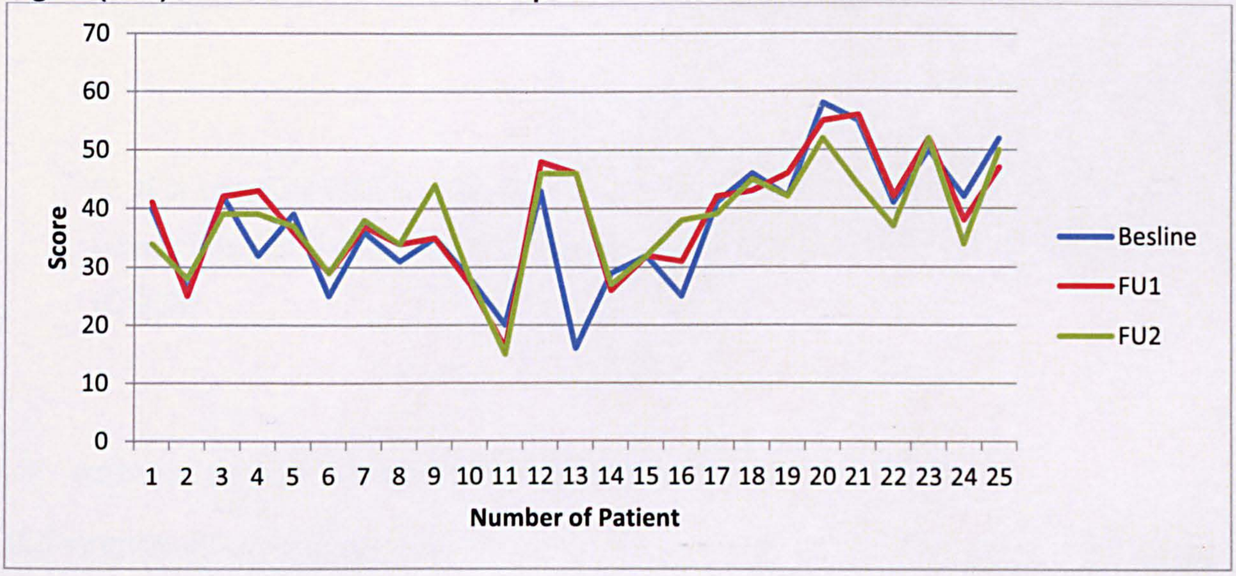
*Comparing the level of satisfaction on first follow up with the second follow up.

A similar comparison was made between first follow up and second follow up. The results were similar to those of the previous comparison with a Mean of (38.76 on first follow up and 37.96 on second follow up. The SD was (9.84158 on first follow up and 8.71053 on second follow up). The p-value was calculated using Wilcoxon Signed Ranks Test and was 0.261 demonstrating no significant change.

*Comparing the satisfaction on three times (Baseline, first follow up and second follow up)

When making this comparison on a larger scale to examine the trends over the three episodes, the findings were as following. The *Mean* was (37.04 on Baseline, 38.76 on first follow up and 37.96 on second follow up), whilst the *SD* was (10.74508, 9.84158 and 8.71053) respectively. The p-value using *Friedman Test* was 0.727. For a better perspective of this comparison please refer to figure 5.18 that presents this trend over the three episodes.

Figure (5.18): Line Chart of Control Group Motivation/Satisfaction



Control group participants identified information as the main motivator for them and likely to make them more satisfied as commented below:

> *"...by knowing things you accept them quicker...As I told you, my sister has glaucoma and I knew at some point I will get...that's why I was going to the optician frequently to check for glaucoma..."* (CG07).

> *"...It is important to know about it as it motivates me and helps me to use my drops...and to know what the consequences of not using them are..."* (CG01).

> *"...It is important for me if for example I decided I am not going to take my drops now I know what is going to happen to me...So in a way it motivates me to take my eye drops on time knowing what the consequences are...Also I think the more you know the less you will be worrying about it and what could happen to you..."* (CG03).

> *"I suppose it does help you when you know what you going through and why you are doing this and that...it stops you from worrying all the time and then you can get on with your life instead of just keep worrying about it..."* (CG06).

> *"...It is very important to know my body and how it is reacting...So I know what things to avoid and what things perhaps I should be doing to help..."* (CG08).

3. Adherence and Concordance (Appendix 5)

Adherence to treatment regimen was also assessed in the same way as the intervention group was assessed by using the same tool.

***Comparing the level of adherence on baseline with first follow up.**

The results were varied with the Mean (2.04 on baseline and 2.28 on first follow up), whilst the SD (2.590 and 2.13151) respectively. The p-value was tested using Wilcoxon Signed Ranks Test and was 0.36.

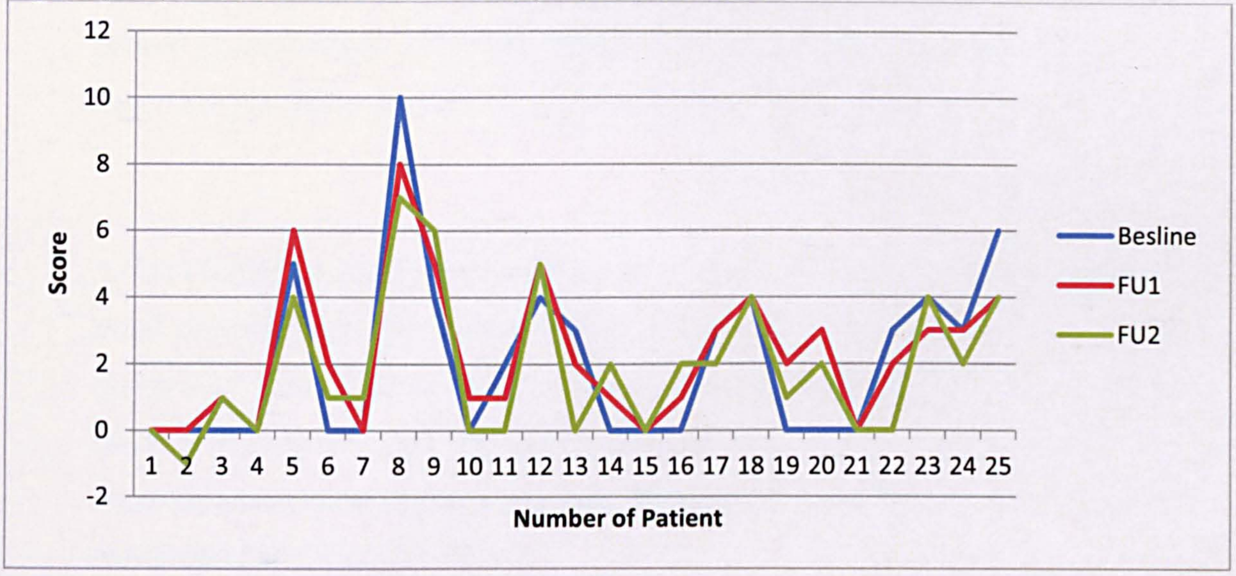
***Comparing adherence on first follow with second follow up.**

A similar comparison was made between the first follow up and second follow up. The mean was (2.28 on first follow up and 1.88 on second follow up) whilst the SD was (2.13151 on first follow up and 2.14709 on second follow up. The p-value was calculated using Wilcoxon Signed Ranks Test and was 0.048 that is significant demonstrating an increase in perceived adherence and concordance.

***Comparing the adherence level on baseline and first follow up and second follow up**

On a larger scale, this comparison was conducted on the three occasions and results were as following. The Mean was (2.04 on baseline, 2.28 on first follow up and 1.88 on second follow up) the SD was (2.59 on baseline, 2.13151 on first follow up and 2.14709 on second follow up) and a p-value was 0.270 using Friedman Test as illustrated in figure (5.19).

Figure (5.19): Line Chart of Control Group Adherence Level



Participants showed uncertainty when it comes to the effectiveness of their treatment. That may have an impact on their concordance levels as indicated in the following narratives:

> *"…The pressure has not gone down…Its rather going up and up…I don't think these drops are doing anything but making my eyes red and gritty…I stopped using them from last week and I will tell them today…"* (CG07).

> *"…Although I am still working and doing the things I used to do…it is only the inconvenience of doing these drops for all this time…especially that I am not totally convinced if I should be putting them at all…"* (CG06).

> *"…They gave me these drops and they keep checking my eyes and saying we will see if things are getting worse or not…but it is bad enough for me and I don't think they are doing anything…That's why I don't like this clinic and I don't think I will come back…"* (CG05).

> *"…Every time I come to this clinic I am seen by some body different…and I find it sort of off putting because you never have the chance to relate to the person treating you…I am much happier when I see the same person*

who probably knows all my history much better than someone who just picked up my notes...I feel like telling them do you actually know me or how much do you know about my glaucoma case..." (CG03).

"I don't think the drops are doing much to me to be honest...The trouble is I don't have a lot of symptoms in first place so it is very hard to tell if I am doing well or not...Sometimes I take the drops religiously and I come to the clinic and they say the pressures are still high...Other times I don't take them regularly and I come here and they say the pressure is normal...So I really don't know..." (CG02).

5.4 Between Groups Comparison

The following table (5.2) presents the quantitative findings from the three groups (Expert Patient Group, Intervention Group and Control Group). It shows the scores of each group on each timeline (Baseline, First Follow Up and Second follow up).

When comparing the satisfaction scores from the Intervention Group with those of the Control Group, one can notice there was a small improvement that was sustained over the 6 months where as in the Control Group it was slightly worse. The same applies to knowledge scores where there is a sustainable improvement in the Intervention Group compared to no improvement in the Control Group. Adherence scores show similar trends when comparing these two groups. Based on these results it can be seen that the GEPP has been successful.

Table (5.2): Average scores of all groups

	Expert Patient Group			Intervention Group			Control Group		
	Satisfaction	**Knowledge**	**Adherence**	**Satisfaction**	**Knowledge**	**Adherence**	**Satisfaction**	**Knowledge**	**Adherence**
Baseline	35.5	23.3	2.0	36.4	20.4	2.0	37.0	19.5	2.0
First Follow Up	30.5	26.5	0	32.1	23.3	0.8	38.8	19.6	2.3
Second Follow Up				33.3	22.9	1.1	37.9	19.9	1.9

Key: **Satisfaction Score:** 1) Extremely satisfied, 2) Satisfied, 3) Neither Satisfied nor Dissatisfied, 4) Dissatisfied, 5) Extremely Dissatisfied. The lower the score the more satisfied the participant. **Knowledge Score:** True and False question, so the higher the score the more knowledgeable the participant. **Adherence Score:** The number of times a participant didn't take his/her eye drops, so the lower the score the more adherence.

In the Expert Patient Group, although deemed as knowledgeable and generally satisfied with the service they received, the scores of knowledge, satisfaction and adherence improved when comparing before and after intervention. This can add an additional value, where the GEPP is not only successful in the above constructs but also for the Expert Patients who delivered the intervention.

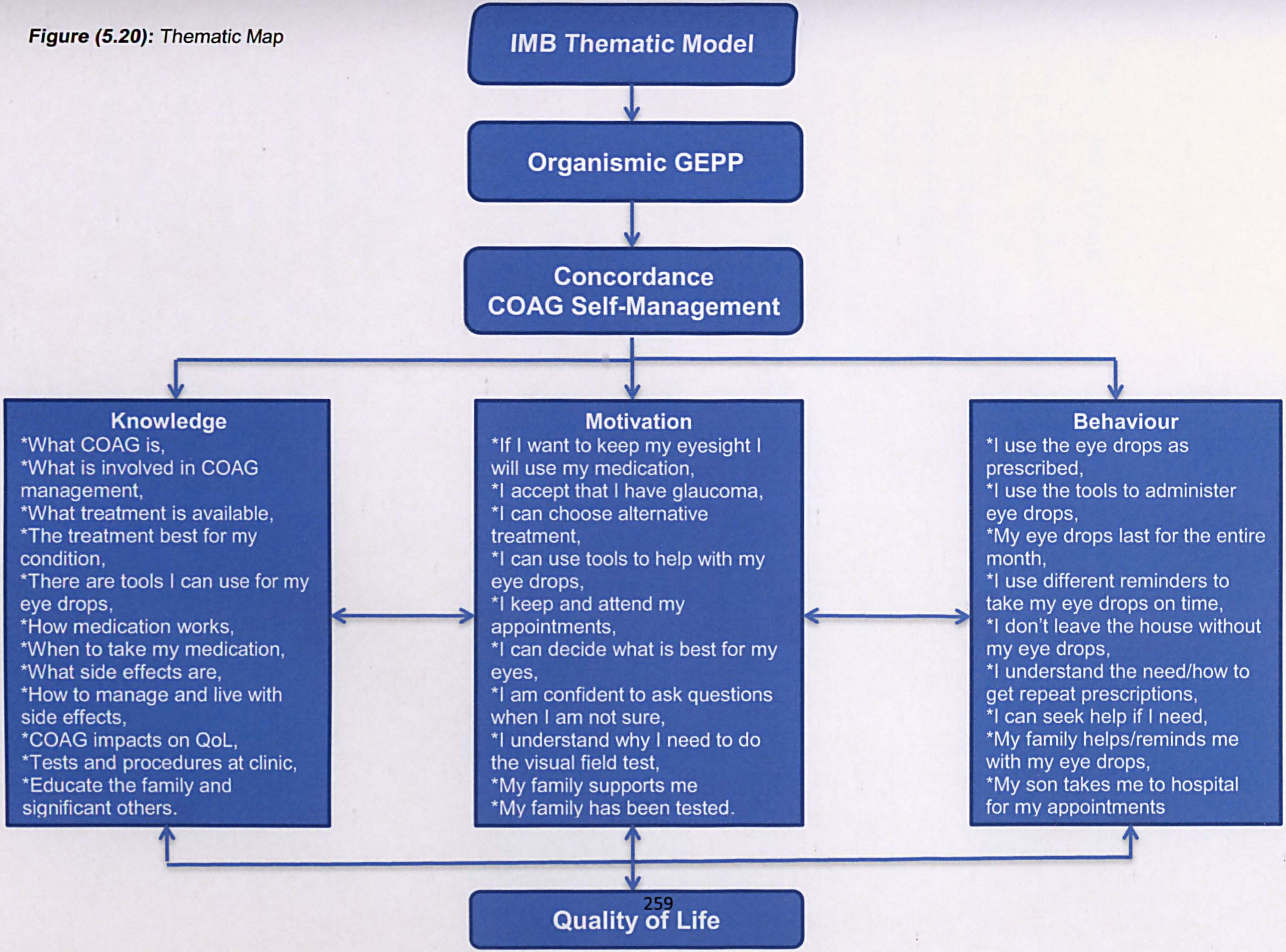
5.5 Thematic Map – Final Results

The following figure (5.20) presents a thematic map that served as an important strategy as it helped focus on the constructs of the IMB model. It has helped in seeing participants' meanings, as well as the connections that participants discussed across sub-themes. Additionally, this map has supported the attempt of embedding data onto the IMB model within the ophthalmic context which is an integral part of this analysis. In the following section, the results of the questionnaires, interviews and field notes are reflected thematically according to the IMB model. The dynamic nature of the model when integrated with the EPP reflects an organismic GEPP. Subsequently patients' knowledge, motivation and behaviour evolve into a substantial platform of self-management of their COAG.

5.6 Summary

This chapter has explicated the results of the GEPP originating with development, extending to implementation and concluding with results demonstrating the outcome of the GEPP. It can be concluded that the development and implementation of the GEPP does improve knowledge and concordance amongst recently diagnosed glaucoma patients. The collaborative approach proposed by this research, as an alternative approach to the medical model has been proved effective, less costly and empowering to newly diagnosed patients with COAG. This tailored self-management programme has the potential to be transferable to other condition in an ophthalmic context.

Figure (5.20): *Thematic Map*



IMB Thematic Model

Organismic GEPP

Concordance
COAG Self-Management

Knowledge
*What COAG is,
*What is involved in COAG management,
*What treatment is available,
*The treatment best for my condition,
*There are tools I can use for my eye drops,
*How medication works,
*When to take my medication,
*What side effects are,
*How to manage and live with side effects,
*COAG impacts on QoL,
*Tests and procedures at clinic,
*Educate the family and significant others.

Motivation
*If I want to keep my eyesight I will use my medication,
*I accept that I have glaucoma,
*I can choose alternative treatment,
*I can use tools to help with my eye drops,
*I keep and attend my appointments,
*I can decide what is best for my eyes,
*I am confident to ask questions when I am not sure,
*I understand why I need to do the visual field test,
*My family supports me
*My family has been tested.

Behaviour
*I use the eye drops as prescribed,
*I use the tools to administer eye drops,
*My eye drops last for the entire month,
*I use different reminders to take my eye drops on time,
*I don't leave the house without my eye drops,
*I understand the need/how to get repeat prescriptions,
*I can seek help if I need,
*My family helps/reminds me with my eye drops,
*My son takes me to hospital for my appointments

Quality of Life

CHAPTER SIX

Discussion

6.0 Introduction

The aim of this study was to explore the issues arising from the development and implementation of hospital-based lay-led Glaucoma Expert Patient Programme (GEPP). The study's objectives were to examine participants' perception of the GEPP, to explore the impact of the GEPP on patient care and its sustainability. In this chapter, implications of the study findings in relation to study's aims and objectives are discussed further and their theoretical and empirical significance explored in relation to future self-management policies. This discussion will also highlight limitations of this study and possible areas of future research.

With all the criticism received, EPPs remain central to the government's self-care policy and aims to equip people with the knowledge and skills that will enable and empower them to assume more responsibility in their care. The literature review (Chapter 3) highlighted that very little is known about EPPs amongst health professionals.

Since its development, the EPP has largely been tailored to be more disease specific. A number of studies have examined the effectiveness of such programmes in various chronic conditions. No work has been identified that designed, implemented or evaluated a glaucoma specific EPP in any setting. This review identified issues that arise from developing and implementing an EPP in an ophthalmic context. Most of the EPPs developed have been conducted in a community setting or General Practice Surgeries. No work has been identified that reports on how to implement such a programme in a hospital setting. There have been no studies that report the process of incorporating an EPP within the daily running of outpatient clinics or how to complement and build on the care provided by health professionals. As this chapter will illustrate, this study serves to address some of these important empirical gaps.

6.1 Reflection on the Methodological Approach

Many of the strengths and weaknesses of research methods used in this study have been discussed in detail in chapter 4. This section reviews the key strengths and weaknesses in light of the findings that emerged so the reader can judge the relevance of the claims made in the remainder of the chapter. A number of strengths in the design of this study give weight to the findings and conclusions drawn. Choosing multiple study designs and pairing qualitative and quantitative methods is valuable as they capitalise on the respective strengths of each approach. This enabled the design and implementation of the GEPP to be examined from a number of different angles and added to the richness of the account given of the study context.

The methodological strength of the ethnographic perspective is in the great importance conferred to the observation of events and rituals, which reveal elements regarding the rules and the culture of the group under study. Ethnography enabled an in-depth view of how ophthalmic care was implemented in a real life clinical setting, therefore, further research into this area should incorporate this approach to inquiry. This design enabled me to build an intense relationship with professionals running the clinics and build a beneficial dialogue. Over a considerable period of time this relationship with on-site presence has allowed me access to multiple opportunities for informal observations and conversations that would have been unavailable through formal data collection techniques alone. These conversations led to new reflections and lines of inquiry which were explicated further in the action research phase. Similarly the action research approach employed a wide range of methods which allowed the GEPP to be implemented and the mixed methods then facilitated evaluation qualitatively and quantitatively; thus giving richness to the account of the study.

The qualitative design allowed the participants' perspectives to be examined. Unlike quantitative methods, qualitatively it was possible to explore and uncover outcomes of participating in the EPP both positively and negatively. Unlike previous qualitative evaluations of self-management programmes which interviewed only participants who successfully attended the 6 sessions of such programmes, the current study interviewed participants who took part and compared the findings with those from a control group. It also took a critical stance toward the data when assessing the impact of the GEPP. Using mixed methods provided the opportunity for triangulation of data derived from the quantitative methods used and so provided contextual information that helped explain the results of the quantitative tools (questionnaires).

Furthermore, my role as an "insider" within this study meant I was in a good position to be accepted as a collaborative researcher. Indeed this gave me further access to knowledge that would not have been available to an external researcher new to the organisation. This arguably adds credibility to study findings although one cannot ignore the bias of being an insider and too close to the data. The democratic impulse in this collaborative form of inquiry is consistent with team working and outcomes suggest action research provides an ideal way to engage participants (patients and staff) in the shared need for improvement.

A further methodological strength was the wide range of methods used to evaluate this inquiry; in particular the use of semi-structured interviews to examine the personal experiences of participants and relating these to findings drawn from the quantitative evaluation.

The sample size used in the quantitative part of this evaluation was relatively small (4 Expert Patients, and 25 patients in the Intervention Group and 25 patients in the Control Group), which is argued to limit the generalizability of the findings. Conversely, the in-depth contextual findings generated resonate with others undertaking similar inquiries, and the potential for generalisation should not be ignored. Additionally, the IMB model tested through the processes of data collection and analysis are more wide applicable beyond this particular setting and has been used to enhance understanding about current practice in today's health service.

6.2 Disease Specific or Generic EPP?

The EPP has provided a new approach to chronic disease management for the 21st century. Unlike all previous papers and interventions of the Department of Health (DoH) the EPP is a user friendly intervention and can be delivered by lay people. However, the argument on the best way forward for the EPP, whether to run a generic or a disease-specific programme, has been long won in favour of the later. Evaluation of generic programmes revealed that participants did not find it beneficial to attend training with participants who don't necessarily suffer from the same condition.

The DoH has compiled evidence in support of successful examples of disease-specific programmes nationally. Since the publication of that evaluation, more successful examples of tailored hospital-based disease-specific EPPs have been developed. The GEPP is an example of an in house self-management programme and resembles a successful attempt to assimilate an EPP into an NHS organisation. In its evaluation of the EPP, the DoH was not successful in engaging NHS organisations to adopt this EPP. Instead, they were faced with endless bureaucracy and lack of access to acute trusts. Being an "insider" and having the support of the leading consultant without a doubt was an advantage that helped obtain the approval of the Research and Development Committee.

Other barriers documented in the DoH evaluation were not as problematic, notably, the lack of legitimacy of lay-led initiatives by health professionals. Moorfields Eye Hospital NHS Foundation Trust is a renowned setting with reputable excellent customer care. Almost all of the professionals I met in this study were in favour of the idea of the GEPP.

6.2.1 Expert Patient Programme as a Vehicle for Patient Empowerment Chapter three explored theories and policies surrounding long-term conditions and in particular those aimed at enabling self-management. The EPP is an example of the commitment of the DoH to making the NHS more democratic and patient-centred as well as eliminating the no longer acceptable medical dominance. Patient and public involvement has been the underpinning of most of the subsequent policies including the EPP as opposed to the current emphasis of evidence based medicine. Beyond this tension other issues were highlighted in participation and involvement. Experts in the field have questioned whether all patients want to participate (Sanders and Skevington, 2003) or whether it is a viable option for all especially when health literacy levels are low (Pickard et al, 2002).

Findings from this study have revealed little if any hesitation from participants in taking part in this study. Expert Patients were particularly enthusiastic about the prospect of taking part in this research and receive the training and support to lead this research. Participants in both intervention and control groups showed great interest in taking part and took this as an opportunity to learn more and make use of the time spent in the waiting area. However, collecting follow up data was not always as straight forward especially with a few participants in the control group who did not attend their follow up appointments. Hesitation in completing the questionnaires could be due to the lack of interest in the study, or lack of knowledge to answer the questionnaires, or both. Subsequently further reminders were sent to participants to complete and return the forms.

Olthoff et al's (2005) review revealed the most successful strategy to improve concordance is by enhancing levels of knowledge and self-management skills. Such strategies are seen as effective mechanisms for self-efficacy and for teaching participants how to set realistic goals that are more likely to be achieved. For the Expert Patients that participated in this study, the experience was something they enjoyed and was an opportunity to gain new knowledge and skills as well. They talked of their improving knowledge base, their increased satisfaction and understanding of the ophthalmic service provided by the Trust. Most of all they expressed the satisfaction they felt from helping and supporting fellow glaucoma patients. It made the experience for them worthwhile.

6.2.2 Common Ground for a Shared Vision

Improving glaucoma patients' concordance level was central to the creation of the GEPP. Despite the large body of published glaucoma concordance literature, the focus is continuing to be on paternalistic solutions to improve concordance. The findings from this study make an important empirical contribution not only to the knowledge it provides, but also to proposing a new collaborative paradigm. This paradigm will shift the emphasis from doing things to patients to empower and enable patients to make informed decisions about their own care and be an active partner. It created a place to bring glaucoma patients and staff to provide a new focus for shared vision and a shared practice where Expert Patient can play a central part in providing healthcare information/guidance to newly diagnosed fellow glaucoma patients. The newly established GEPP has helped to define the core purpose and value of actions to be undertaken by the Expert Patients, and providing common ground for shaping a shared understanding as a base for collaborative working.

6.2.3 NHS Cost-Cutting and Challenge Ahead

The NHS is facing a tough financial climate, and cost cutting is on everyone's agenda, with trusts across the country having little time before the financial axe falls. Although it is unclear how much needs to be saved across the NHS, it is inevitable that cost cutting will reduce the quality of care. The McKinsey report sets out a range of advice to enable NHS organisations to achieve suggested savings. Of which they suggested increasing professionals' patient facing time, in other words, reducing the number of health professionals and increasing the number of patients seen by professionals per day. This means professionals will have even less time to spend with patients and that will inevitably impact the quality of glaucoma care and indeed the overall health care in the NHS.

Findings from the Ethnographic phase of this study support theory that states work that is not viewed as core work to a profession regardless of the reason, is at risk of being marginalised (Sheppard et al, 2003). Findings showed that professionals were, on occasions at least, practicing under large pressure and so were unable to provide all information and care they would normally provide. The occasions identified became more frequent as numbers of patients referred and reviewed in these outpatients clinics are constantly increasing. This lack of time and workload is likely to become a norm with the cost cutting measures as discussed earlier and so a key solution needs to be unearthed. Does this not substantiate the need for instituting a GEPP?

Without taking away any of the traditional responsibilities of professionals in being informative and engaging with patients, the challenge ahead needs new arrangements that can blend professional and patients expectations to set reasonable goals. This will require effort and innovation in finding new solutions and strategies for the turbulent near term future. The GEPP gives an ideal example of this innovation. It provides an affordable and ethical alternative by engaging experienced patient to play an essential role in improving the service provided and complement the efforts of the professionals. This will require a more integrated and coordinated services which can be achieved through good team work and improving communication.

As the GEPP provided space for patients to come together for mutual engagement in glaucoma care, and in doing so they developed a sense of identity as the 'Expert Patient' working with professionals in the clinics. This identity has developed a sense of belonging to this community and the outpatient clinics. The Expert Patients that participated in this study no longer felt as strangers to the outpatient clinics.

6.3 The IMB Model Constructs

Findings of the three main constructs of the IMB model were consistent with findings from previous studies. There was a statistically significant improvement in level of knowledge amongst participants from the intervention group and to lesser extent in participants from the control group. This improvement in knowledge correlated with an improved level of satisfaction with the five main aspects of their treatment as illustrated in previous chapter as well as improved behavioural skills. A relatively weak correlation with adherence was demonstrated in the findings using the self-administered questionnaire to measure the rate of non-adherence. The self-report has an advantage of being relatively simple and inexpensive. The risk of recall bias is minimised in this study by asking for non-adherence only in the past 4 weeks. Over-estimation risk was dealt with by strict definition of the low cut-off level of non-adherence.

I tried to explore the relation between participants who have a very poor adherence level and their level of knowledge about their glaucoma and their treatment regimen. However, because only a few participants did not use their medication more than 10 times in the last few weeks; therefore analysis on this subject should not be considered reliable. But looking at individual cases, participants who were less compliant to their glaucoma treatment were generally less knowledgeable and dissatisfied with the service and the treatment received.

The IMB model suggested that improving the level of knowledge and improving behavioural skills and motivation will improve levels of satisfaction and ultimately improve concordance levels. Of course, I would prefer to have shown that improvement of knowledge would lead to great improvement of concordance with glaucoma treatment. The lack of significant improvement of the concordance level amongst participants can be related to many reasons. First, the study sample was relatively small and so the improvement was not large enough to be represented in the p-value. Secondly, self-report as a tool, as mentioned earlier, has recall bias which could have affected the results of this study. Thirdly, participants who are adherent to their medication are more likely to volunteer to take part in the research affecting study results. In addition, the likelihood of being patients in the outpatient clinics may mean that they are more eager to discuss their condition and take part, or both.

6.4 Empirical Contributions

Whilst this study directly builds on the existing knowledge and research literature in glaucoma concordance, insights generated by this in-depth inquiry contribute to knowledge about designing and implementing a GEPP and provides the first empirical account of processes involved in setting up such a programme within a clinical setting. Furthermore, findings related to the central role of the Expert Patient in conducting this inquiry add empirical support to the growing recognition of the patient-centred collaborative approach for healthcare and health research. Thus this Thesis adds to practice based knowledge, the *knowing how*, of the implementation and delivery of an EPP in an ophthalmic context. In addition, findings from this research are significant as they provide the first empirical account of how a GEPP was created for delivery in a clinical setting by an Expert Patient.

This Thesis demonstrates that Ethnography and Action Research provide a sound mechanism for improving services in the NHS as Greenhalgh et al (2004) have indicated. In particular, findings suggest the democratic and collaborative approaches of action research are congruent with the development of the GEPP, a concept recently introduced by the DoH as a way to democratise the NHS.

This research has implications for healthcare policy as the ageing population increases and as treatment concordance potentially becomes an increasingly challenging and costly problem. This research also provides important information to guide the development of interventions to improve glaucoma concordance based on the participatory paradigm.

6.5 Theoretical Contributions

This study demonstrated strong theoretical links between the findings and the creation of the GEPP based on the IMB model. This study makes an important new contribution to the theories of adherence. It illustrates how to apply the IMB model in a new context like the ophthalmic context which is beyond the point of its establishment of being a model for HIV/AIDs intervention. The role of the IMB model construct in predicting and improving concordance was tested in this study.

Finally, the IMB model has specified situations in which information is expected to be a significant contributor to concordance and when it will not. Further empirical study of the IMB model's conceptualisation of the role of knowledge is necessary. More clarification is required concerning the relationship between knowledge and motivation constructs which are sometimes independent and sometimes not. The IMB model logic which holds that well-informed people are not necessarily well motivated and vice versa is shown, and so it is important to establish conceptually when such a relationship may or may not be anticipated by the theory.

6.6 Conclusion

The current financial climate has taken most of the attention on how best to cut the cost of the NHS and employ strategies to save more money. With the quality of care ultimately on the line, the EPP as an affordable ethical and feasible programme, can provide answers to many doubts and concerns regarding the future of the NHS. In a time where every penny counts, the EPP can contribute significantly to improving patients' satisfaction with the service and treatment they receive in the glaucoma outpatient clinics. It also could give patients more say on how the service is run and how best to improve it. The GEPP has been the first of its kind in an ophthalmic context; it proves a success and has the potential to be incorporated into other services at Moorfields Eye Hospital NHS Foundation Trust and other ophthalmic facilities where adherence is an issue.

CHAPTER SEVEN

Conclusion

7.0 Summary

The aim of this ethnography, action research and mixed methods study reported in this Thesis was to develop, implement and evaluate a GEPP. This programme was initiated in four glaucoma outpatient clinics and delivered by Expert Patients who played a central role in its design and delivery. The study aimed to describe critically the processes involved in such an initiative and examine the effectiveness of the GEPP in improving knowledge and concordance amongst newly diagnosed glaucoma patients.

This study achieved most of its objectives. During the Exploratory phase of the study, using an ethnographic approach, it set out to understand and explore the practices followed in the clinic. Great consideration was given to incorporate input from various key players and the expressed needs of patients into the GEPP design. As a result, two major action cycles were implemented using a collaborative approach to implement the GEPP. This approach has ranged from “technical collaborative” in the early stages of this study and progressed to a “mutual collaborative” approach at later stages. Expert Patients were encouraged and coached into taking a central role in this inquiry by collaborating with the research team and patient participants. The study has been evaluated using a mixed methods approach.

7.1 Key Findings

This section highlights some of the key findings reported more fully in previous Chapters 5 and 6.

7.1.1 Ethnography Phase

During the exploratory phase of the study, the research highlighted that an increasing workload and time constraints impacted on the quality of care provided to glaucoma patients. Many staff were interested and committed to the provision of high quality care, but a lack of time and space within the glaucoma outpatient clinics meant that care provided, at times, fell short of the usual and desired standard.

7.1.2 Action Phase

The EPP in its generic form has little if any relevance to patients with chronic eye conditions such as glaucoma. The generic form failed to engage 'hard to reach' groups whom policy makers wished to target. Action research emphasised a collaborative approach and allowed problems and their respective solutions to be identified. Action research revealed solutions that made the EPP format more palatable. It encouraged, facilitated and ultimately engaged participants in helping to shape the GEPP in a way that is responsive to their needs and provides the self-care support required. The GEPP developed in this study is an example of a modified EPP that has the potential to play a major part in helping people live with glaucoma. Unlike the DoH plan of providing the EPP as a part of community social network, I argued that disease specific self-management programmes like the GEPP can be incorporated as part of the clinical setting to complement the care provided by professionals and fill the gaps where they have failed. The GEPP provides a successful example of how such a programme can be entwined within the NHS and how the envisaged value of a self-care approach can be achieved.

7.1.3 Evaluative Phase

The GEPP can be described as a complex intervention where it is difficult to work out cause and effect mechanisms. Unlike other EPPs, this programme has a technical and practical focus, in the sense that participants have been exposed to technical terms and procedures, relevant information and practical and essential skills to help them self-care. The GEPP has significantly improved the level of knowledge amongst participants and, to an extent, improved their level of satisfaction with the service and the care they receive in the clinic.

7.2 Implications of this Research

This study has raised some important issues which are worthy of future consideration. The issues raised are related to future practice and research and likely to be of specific interest to health professionals, researchers, educationalists, managers and policy makers in the ophthalmic field and more generally in chronic disease self-management.

7.2.1 Future Practice

1. The EPP, in its generic form, needs to move away from rigid material delivery and demonstrate more flexibility and responsiveness to the particular needs of participants.

2. The EPP can be tailored into a more flexible form such as the GEPP and so potentially be incorporated into clinical settings where it becomes a routine part of the service. This can ultimately improve patient and public involvement.

3. After a number of years since being launched, health professionals seem to have very little knowledge of the EPP initiative and the notion of Expert Patients. Providing a disease-specific EPP in the clinical setting would potentially expose health professionals to this concept.

4. There is a need for health professionals (nurses, optometrists and ophthalmologists) to recognise and value the vast experience gained by patients along their journey and life with glaucoma. Finding innovative strategies and ways to involve experienced patients to be part of this service would appeal to commissioners and the general public, simply because it is ethical, democratic and affordable.

5. In the event of implementation of the GEPP, careful reviews need to be undertaken to ensure that important aspects of nursing and medical responsibilities toward patient care are not marginalised.

6. Nurse specialists involved in this research felt less challenged by the Expert Patients and were consequently able to enter into an appropriate therapeutic relationship with them. The nurse specialists showed confidence in their knowledge,

which created a sense of openness and encouragement when patients did question treatment options.

7. Nurse Managers involved in this study showed a firm commitment and appreciation of the idea of the GEPP and demonstrated a preparedness to continue playing the facilitator role if this programme were to be implemented more comprehensively in the future.

8. This study proposes a new collaborative approach to the management of COAG with a move away from the paternalistic approach traditionally followed. The traditional approach has historically failed to provide answers to the challenge of concordance in the management of COAG.

9. Despite the efforts made by the medical profession to adapting the medical curriculum to incorporate more emphasis on communication skills and partnership relationships with patients, there appears to be a continuing adoption of the acute care model which does not facilitate patient involvement. Such an approach compromises the opportunity for concordance to develop.

7.2.2 Future Research

1. Understanding the issues of concordance in conditions like glaucoma indicates that subsequent interventions should be based on solid theoretical underpinning. This study used the Information-Motivation-Behavioural Skills model which worked successfully in explaining the adherence behaviour and supporting the development of the GEPP and its evaluation.

2. Evaluation of complex interventions like glaucoma concordance requires an increase in the use of practice based and action orientated approaches that take into account processes and the wider socio-economic and contextual factors, such as ethnography and action research.

3. Increased funding opportunities to encourage healthcare professionals to undertake qualitative practice based research should be considered. Funding bodies need to recognise the value and importance of the context that can be gained by using qualitative or mixed methods.

4. Findings from this study suggest that patients can play a central role in research and be successful co-researchers. More effort should be made to engage patients not only as subjects but as part of the research team.

5. There is a need for further research to explore whether results achieved in this study can be replicated in different settings and with conditions other than glaucoma.

7.3 Conclusion

The research explicated in this Thesis has identified issues that influence and affect patients with COAG self-management skills. The unique priorities and needs of patients living with COAG include, but rarely limited to, problems with medication use. The GEPP developed in this study provided information, motivation, and behaviour skills support for medication use and adherence within a broader patient-centred system of care delivery that "activates" patients and improves their health outcomes.

Findings from this study also highlight that efforts to support effective self-management require patient motivation and should begin with a collaborative approach to help patients determine their unique needs and concerns. Importantly, the findings highlight that the EPP can contribute to improving the lives of people who are living with a long-term condition such as COAG. It is only by moving away from the inflexible generic programme and adapting a more flexible approach like the GEPP that service delivery can be more responsive to patients' needs.

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Appendix (1)

Observation Data

Patient Information

- **GLAUCOMA:**

What is glaucoma? Yes ☐ No ☐

Was treatment given? Yes ☐ No ☐

If yes:

Why they were given? Yes ☐ No ☐

For how long to be used? Yes ☐ No ☐

Where to get a repeat prescription if needed? Yes ☐ No ☐

Self-management and self-care? Yes ☐ No ☐

- **FUTURE VISITS:**

Prognosis of glaucoma if untreated? Yes ☐ No ☐

Tests and procedures to be carried out on future visit? Yes ☐ No ☐

- **OTHER ISSUES:**

Family screening? Yes ☐ No ☐

Driving? Yes ☐ No ☐

Appendix (2)

Expert Patient: Checklist

This list is intended to help us decide your suitability for this role. Please take the time to think about them or discuss with us before you take any further steps to volunteer for the COAG Self-Management Programme.

1. What is my motivation?
2. Am I a good listener?
3. Can I commit to training sessions regularly and reliably?
4. How much experience do I have in self-managing my own glaucoma?
5. Can I work with a small group of people and build a rapport with them?
6. Have I already explored / dealt with my own feelings about having a chronic glaucoma?
7. Will I be able to accept and build on feedback from others?
8. Am I ready to learn new ways of approaching long-term health conditions?
9. Can I facilitate rather than dominate?
10. Do I feel I am an effective communicator?
11. Do I have the time available for the training programme?
12. Am I willing to travel out of my home area as necessary?
13. Am I adaptable to working with different people?

Appendix (3)

Moorfields Eye Hospital NHS Foundation Trust

Glaucoma Patients' Knowledge Questionnaire

Patient ID for Study: __________

Visit: Baseline / 1-3 months / 6 months (circle as appropriate)

The following are statements about glaucoma; please circle (T) if you think it is TRUE or (F) if you think it is FALSE.

Statement	True	False
1. If the visual field is impaired, this can be repaired.	T	F
2. Young people more often have glaucoma than older people.	T	F
3. Glaucoma often causes impaired reading.	T	F
4. Glaucoma affects the visual field.	T	F
5. The optic nerve is damaged in glaucoma.	T	F
6. It is possible to have glaucoma without knowing.	T	F
7. Without treatment, glaucoma is a FAST progressing condition.	T	F
8. Nutrition influences glaucoma.	T	F
9. The chance of getting glaucoma is higher if a family member has glaucoma.	T	F
10. The intraocular pressure is increased if it exceeds 25.	T	F
11. The chance of getting glaucoma is higher if the intraocular pressure is increased.	T	F
12. The patient should tell the ophthalmologist which other diseases she/he has or medicines she/he is using.	T	F
13. Glaucoma causes reduction of visual acuity.	T	F
14. African people have a higher chance of getting glaucoma.	T	F
15. Being very short-sighted or long-sighted gives a higher chance of getting glaucoma.	T	F
16. The intraocular pressure is always increased in glaucoma.	T	F

The following are statements about glaucoma treatment; please circle (T) if you think it is TRUE or (F) if you think it is FALSE.

atement	True	False
Early detection and treatment will NOT slow down the course of glaucoma.	T	F
Laser treatment or surgery for glaucoma can repair the damage caused by .aucoma.	T	F
Some eye drops should not be used by cardiac patients or asthma patients.	T	F
A slower heart rate could be an adverse effect of eye drops.	T	F
Shortness of breath could be an adverse effect of eye drops.	T	F
Each treatment is equally good for everyone.	T	F
Stinging or burning of the eyes could be an adverse effect of eye drops.	T	F
Eye drops can be replaced by tablets.	T	F
The course of the disease can be slowed down by eye drops.	T	F
). A high intraocular pressure must always be treated.	T	F
l. Discoloration of the iris may be an adverse effect of eye drops.	T	F
2. Blurred vision after using eye drops could be an adverse effect of the .edication.	T	F
3. Even if the intraocular pressure is under control, the visual field has to be ıecked.	T	F

Appendix (4)

Moorfields Eye Hospital NHS Foundation Trust
Glaucoma Patient's Medication Use

Patient ID for Study: ____________

Visit: Baseline / 1-3 months / 6 months (circle as appropriate)

How many times you have not used your glaucoma medication in the past four weeks as instructed? Please circle the correct answer.

0 1 2 3 4 5 6 7 8 9 10 >10

☐ **I do not take any eye drops.**

Moorfields Glaucoma Expert Patient Study

Appendix (5)

Moorfields Eye Hospital NHS Foundation Trust
Glaucoma Patients' Treatment Satisfaction Questionnaire

Patient ID for Study: ________

Visit: Baseline / 1-3 months / 6 months (circle as appropriate)

Please indicate your degree of agreement with the following statements by placing a circle on the appropriate number representing your answer. There are no right or wrong answers - we are simply interested in your views.

Statement	extremely Satisfied	Satisfied	Neither Satisfied/ Dissatisfied	Dissatisfied	Strongly Dissatisfied
Effectiveness:					
1. How satisfied or dissatisfied are you that the eye drops are preventing future vision problems?	1	2	3	4	5
2. How satisfied or dissatisfied are you that your eye drops are reducing current vision problems?	1	2	3	4	5
Convenience of use:					
3. How satisfied or dissatisfied are you with the number of times per day you are required to use your eye drops?	1	2	3	4	5
4. How satisfied or dissatisfied are you with the time of day that you are required to use your eye drops?	1	2	3	4	5
5. How easy or difficult is it to remember to use your eye drops at the time of the day they should be used?	1	2	3	4	5
Ease of administration:					
6. How easy or difficult is it to deliver the required amount of eye drops to the eye without missing or applying too much medication?	1	2	3	4	5
7. When standing up, how easy or difficult is it to correctly angle your head to accurately apply the eye drops?	1	2	3	4	5
8. How confident are you in your ability to consistently get exactly the right amount of eye drop medication (one drop) in your eye each time you use it?	1	2	3	4	5

Statement	extremely Bothered	Bothered	Neither Bothered/ Not Bothered	Not Bothered	Strongly Not Bothered
Side effects: 9. How much are you bothered by prolonged burning or stinging as a result of using your eye drops?	1	2	3	4	5
10. How much are you bothered by grittiness or sandiness in your eyes as a result of using eye drops?	1	2	3	4	5
11. How much are you bothered by unpleasant feelings of stickiness or crustiness in or around your eyes due to using eye drops?	1	2	3	4	5
12. How much are you bothered by dry eyes due to using your eye drops?	1	2	3	4	5
Eye appearance: 13. How much are you bothered by people's reaction or comments about the redness of your eyes caused by using your eye drops?	1	2	3	4	5
14. How self-conscious have you been of eye redness caused by your eye drops?	1	2	3	4	5
15. How concerned have you been by changes to the overall cosmetic appearance of your eyes due to redness caused by using your eye drops?	1	2	3	4	5

Appendix (6)

Scenario1. (Compliance)

Patient:

A 58 years old taxi driver was diagnosed with glaucoma 3 months ago; he was given a beta-blocker to be applied topically twice a day. On the next his wife says he is not taking the medications regularly. The patient does not think it is important to do so and thinks it is enough to do it once a day or even twice a week.

Expert Patient:

Drug non-compliance is a common problem. Avoid confronting the patient as the patient may deny it. Instead begin by asking if he had problems with the eye drops such as breathlessness and any problems applying them such as rheumatoid hands. Then explain to him the deterioration of visual field and the risk of blindness and losing his driving license. Suggest discussing alternatives with the doctor rather than not using the drops.

Scenario2: (Side Effects)

Patient:

A 62 years old lady with a strong family history of glaucoma was diagnosed with glaucoma five months ago. It was a bit of shock for her as the case with most glaucoma patients as she was asymptomatic. As she understood the risks accompanied with glaucoma she was very religious in applying the eye drops on time as prescribed. However, she started experiencing burning and red eye as a result. She thinks her eyes were fine until she start using the drops which gave her a lot of discomfort.

Expert Patient:

Most glaucoma patients will experience side effects to their eye drops, however, that should not stop them from taking the drops. Explain to this lady the importance of taking these eye drops and encourage her to discuss the side effects with the doctors as she might be allergic to them.

Scenario3: (No Problems Subjectively)

Patient:

A 52 years old man has been referred by his (Optician then GP) to the clinic as glaucoma suspected. After extensive testing and examination the diagnosis was confirmed as open angle glaucoma. The patient never experienced any problems subjectively and always has had good eye sight.

Expert Patient:

The difficulty with glaucoma is that in the vast majority of cases patients do not notice anything at all "asymptomatic". Explain to the patient that glaucoma patient most of the times do not experienced any symptoms as the deterioration of vision is in the periphery more than central, it is gradual in onset and painless that it can go easily unnoticed.

Scenario4: (What is Glaucoma?).

Patient:

A 68 years old man was recently diagnosed with glaucoma. Although it was previously explained to him but he does not seem to understand what glaucoma is. He is taking his drops regularly and his pressure is brought under control.

Expert Patient:

Terminology and amount of information given to patient once the diagnosis has been confirmed could be overwhelming. In simple language describe to this man what glaucoma is, what the purpose of the treatment, what are the risks of glaucoma, what are the targets when treating glaucoma.

Appendix (7)

INFORMATION SHEET

FOR EXPERT PATIENT VOLUNTEERS

Implementation and evaluation of an Expert Patient Programme for patients with chronic primary open angle glaucoma

You are being invited to take part in a research study. Please read the following information carefully and do not hesitate to ask if anything is unclear or you need more information.

This study has been reviewed and approved by the Moorfields & Whittington Research Ethics Committee.

What is the purpose of the study?

The purpose of this study is to understand the impact of involving expert patients with glaucoma to help other glaucoma patients to better understand their eye condition and to learn how to live with a lifelong condition.

You will be welcome to offer suggestions or input from your own experience with the illness and with the service that you have been receiving on how to improve the Expert Patient's role in helping other newly diagnosed glaucoma patients.

Why have I been chosen?

You have been invited to take part as you have been diagnosed and living with glaucoma for the past few years. We will be inviting three other Expert Patients to draw on their experience on how to make the service a better one.

Do I have to take part?

No. it is voluntary and up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason. Should you decide not to take part or withdraw your standard of care will not be affected.

What will happen if I participate?

You will be asked to complete a short questionnaire on some background information on yourself prior to taking part in the project, and then you will be invited to take part in an interview and a focus group to explore issues related to self management and the service you are receiving.

You will need to make one visit to the hospital for training, which will take 4-6 hours. You will receive training and all the information and support you need to enable you to teach other patients about their condition in sessions of 20-30 minutes.

You will also be invited at the end of the study in another focus group meeting to give us feedback on your experience and your evaluation of the entire experience. All expenses (e.g. travel and refreshments) will be paid for throughout the study plus £25 in gift tokens, as a "thank-you" gift at the end of the study.

How long will it all take?

The questionnaire should take approximately five to ten minutes to complete.

Focus groups will be held twice; one at the beginning of the study on an agreed date in which we will explore with you different issues regarding your illness, self-management as well as issues regarding the service and care you are receiving in the Glaucoma Clinic. The other focus group will be toward the end of the study in which we will welcome any feedback on your experience. If you prefer a one-to-one interview with the researcher over focused groups, we will arrange for an agreed date between you and the researcher.

Each session with patients will take anything from 20-30 minutes. The number of patients receiving the training will depend on how many patients agree to take part in the study. We aim to recruit 5 patients for each Expert Patient.

What are the possible benefits of taking part?

This experience will:

- Offer you greater awareness of the principles of self management of glaucoma
- Make a valuable contribution to the way we run the service and to the self-management agenda.
- Allow you to work closely with health professionals who are caring for you and other glaucoma patients.
- Increase your awareness and confidence in relationships between patients with glaucoma and staff involved in patient self-management.

What if you have a complaint?

Any complaint about the way you have been dealt with during the study will be addressed. You should contact Sue Lydeard, Research Manager on

Will my taking part in this study be kept confidential?

Yes, all information collected and views given in the course of this study will be recorded onto forms for analysis and kept securely under the terms of Data Protection Act 1998. All information which is collected about you during the course of the research will be kept strictly confidential. If you agree to take part in the study, your GP will be informed of this.

What will happen to the results of the research study?

Theoretical contributions of this study will be disseminated to academic audiences. Evidence from this study will be published on the requirements and the implications of self management training. The learning from practice will be fed back to inform the future development of policies and practices.

Contact: if you have any questions please call Raed Amro at Moorfields Eye Hospital on

Please note that participation in this study is entirely voluntary and you will not be at any disadvantage if you decide not to take part.

Appendix (8)

INFORMATION SHEET
FOR CLINIC PATIENT PARTICIPANTS

Implementation and evaluation of an Expert Patient Programme for patients with chronic primary open angle glaucoma

You are being invited to take part in a research study. Please read the following information carefully and do not hesitate to ask if anything is unclear or you need more information.

This study has been reviewed and approved by the Moorfields & Whittington Hospitals Research Ethics Committee.

What is the purpose of the study?

The purpose of this study is to understand the impact of involving Expert Patients with glaucoma to help other glaucoma patients to better understand their eye condition and to learn how to live with a lifelong condition.

You will be welcome to offer your feedback on the performance of the Expert Patients and how effective you think they are in helping you to make the most of your clinic visits and your time at the hospital.

Why have I been chosen?

You have been invited to take part as you have been diagnosed with glaucoma. We will be inviting approximately 20 patients to take part.

Do I have to take part?

No. it is voluntary and up to you to decide whether or not to take part. If you do, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw from the study at any time without giving a reason. Should you decide not to take part or withdraw your standard of care will not be affected.

What will happen if I participate?

If you agree to take part in the study, you will be asked to complete 3 short questionnaires whilst you waiting to see your doctor or receive your medications. These questionnaires will take about 20 minutes in total to complete and will address issues such as: knowledge of your condition; compliance with medication; and satisfaction with the care you are receiving.

You will then be introduced to an Expert Patient, who will tell you more about your condition, answer any questions you may have, and give you advice on how to manage your symptoms. This session with the Expert Patient should last between 20-30 minutes.

Approximately 1-3 months after this session with the Expert Patient, and then again at 6 months, we will ask you to repeat the same 3 questionnaires you will have completed at recruitment. The information you give us will help us to ascertain the effectiveness of involving Expert Patients in the service.

What are the possible benefits of taking part?

You will have the chance to informally talk with a patient who is suffering the same illness as you and an expert in managing their condition.

What if you have a complaint?

Any complaint about the way you have been dealt with during the study will be addressed. You should contact Sue Lydeard, Research Manager on

Will my taking part in this study be kept confidential?

Yes, all information collected and views given in the course of this study will be recorded onto forms for analysis and kept securely under the terms of Data Protection Act 1998. All information, which is collected, about you during the course of the research will be kept strictly confidential. If you agree to take part in the study, your GP will be informed of this.

What will happen to the results of the research study?

Theoretical contributions of this study will be disseminated to academic audiences. Evidence from this study will be published on the requirements and the implications of self-management training. The learning from practice will be fed back to inform the future development of policies and practices.

Contact: if you have any questions please call Raed Amro at Moorfields Eye Hospital on

Please note that participation in this study is entirely voluntary and you will not be at any disadvantage if you decide not to take part.

Appendix (9)

CONSENT FORM

FOR CLINIC PATIENT PARTICIPANTS

Title of Project: Implementation and evaluation of an Expert Patient Programme for patients with chronic primary open angle glaucoma

Name of Researchers: Raed Amro, Dilani Siriwardena, Carol Cox

Please initial box

1. I confirm that I have read and understood the information sheet dated 04.06.2009 (Version 1.1) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected. ☐

3. I understand that relevant sections of any of my medical notes and data collected during the study may be looked at by responsible individuals from this Hospital, from regulatory authorities or from the NHS Trust, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my records. ☐

CONSENT FORM (continued)
FOR CLINIC PATIENT PARTICIPANTS

Title of Project: Implementation and evaluation of an Expert Patient Programme for patients with chronic primary open angle glaucoma

Name of Researchers: Raed Amro, Dilani Siriwardena, Carol Cox

Please initial box

4. I agree that my GP can be informed about my participation in the study. ☐

5. I agree to take part in the above study. ☐

________________	________________	__________
Patient Name	Signature	Date
________________	________________	__________
Researcher	Signature	Date

Appendix (10)

Publications

Glaucoma expert patient programme

Abstract

Expert patient programmes (EPPs) are becoming an increasingly important aspect of chronic disease management, resulting in improved health outcomes for patients. Patients with chronic open angle glaucoma (COAG) require lifelong therapy. However, to date, no EPPs have been designed specifically for patients with chronic eye conditions like COAG. This article describes the development and implementation of the Glaucoma Expert Patient Programme (GEPP), a glaucoma-specific educational self-management programme which aims to improve glaucoma patients' knowledge, self-management skills, expectations and adherence to treatment. A review of theoretical frameworks and models which underpin the design, use and conduct of EPPs was undertaken, and the GEPP was designed based on the model by Kate Lorig (2003). The result is an educational programme which offers COAG patients a different perspective on their condition and supports them with knowledge, skills and strategies to better manage their condition on a daily basis.

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Patients with chronic open angle glaucoma (COAG) require lifelong therapy. Successful treatment outcomes require the daily instillation of ocular hypotensive eye drops to prevent the occurrence of glaucoma, if intraocular pressure is high, and to delay the progression of visual fields loss (Olthoff et al, 2005). More than ever before, patients are assuming greater responsibility for their care, becoming experts in managing their symptoms, daily administration of their medication, and communicating their needs and concerns with health professionals. However, asymptomatic diseases like COAG are prone to poor patient adherence in following treatment plans (DiMatteo et al, 2002).

A number of authors have suggested that the nature of COAG fosters non-adherence, with minimal chances of maintaining eyesight among patients who adhere poorly to treatment (Stewart et al, 1993). Poor adherence not only leads to poor health outcomes, but also unnecessarily increases healthcare costs (Haynes et al, 2002).

Discussions of adherence often detract from the reality of patient independence in self-managing their condition (Gifford and Groessl, 2002). By focusing attention on the power held by health professionals, there is a risk of discouraging collaborative problem solving that addresses patient motivation and barriers to the taking of medication (Steiner and Earnest, 2000).

Self management and expert patient programmes

Self-management programmes for patients with COAG are rare. It is postulated here that learning from the experiences of patients with other chronic conditions who have been through an expert patient programme (EPP) can provide useful guidance in establishing a glaucoma self-management programme. The concept of patient self-management first emerged in the 1960s and 1970s as a method for finding better solutions to living with chronic illness. The first structured self-management programme was developed by Lorig and colleagues (1999). In this scheme, self management is seen as an integral, even central, part of the system of care provided to people with chronic diseases (Department of Health (DoH), 1999). This approach to the management of chronic disease, or long-term conditions, has been taken up in many countries around the world, including Australia, China, South Africa, Canada, and many European countries, including the UK.

Based on Lorig's model, the DoH established the Expert Patient Programme as a lay-person-led self-management programme designed specifically for people living with long-term conditions (Department of Health, 1999). The aim of this programme is to support people by increasing their confidence, better managing their condition and subsequently improving their quality of life. The DoH identified the most common chronic diseases that have a significant impact on a person's quality of life and on their family among the UK population. These are arthritis, asthma, back pain, diabetes mellitus, epilepsy, heart failure and multiple sclerosis (Department of Health, 2002). Having been successfully piloted, the EPPs for arthritis and some other chronic diseases currently offer around 12 000 course places every year. These are made available through NHS trusts in primary care and partner organizations (Department of Health, 2009). Internal evaluation data from approximately 1000 EPP participants, who completed a course between January 2003 and January 2005, indicates that the programmes are achieving improved health outcomes for patients and reduce the degree to which these patients use healthcare services (Department of Health, 2005).

Glaucoma expert patient programme and ocular hypotensive treatment

Raed Amro, Carol L Cox, Kathryn Waddington, Dilani Siriwardena

Abstract

Expert patient programmes (EPPs) are becoming an increasingly important aspect of chronic disease management, resulting in improved health outcomes for patients. Patients with chronic open angle glaucoma (COAG) require lifelong therapy. However, to date, no EPPs have been designed specifically for patients with chronic eye conditions like COAG. This article describes the development and implementation of the Glaucoma Expert Patient Programme (GEPP), a glaucoma-specific educational self-management programme which aims to improve glaucoma patients' knowledge, self-management skills, expectations and adherence to treatment. A review of theoretical frameworks and models which underpin the design, use and conduct of EPPs was undertaken, and the GEPP was designed based on the model by Kate Lorig (2003). The result is an educational programme which offers COAG patients a different perspective on their condition and supports them with knowledge, skills and strategies to better manage their condition on a daily basis.

Key words: Expert patient programme ■ Glaucoma expert patient programme ■ Self-management programme ■ Information-motivation-behavioural skills model

Patients with chronic open angle glaucoma (COAG) require lifelong therapy. Successful treatment outcomes require the daily instillation of ocular hypotensive eye drops to prevent the occurrence of glaucoma, if intraocular pressure is high, and to delay the progression of visual fields loss (Olthoff et al, 2005). More than ever before, patients are assuming greater responsibility for their care, becoming experts in managing their symptoms, daily administration of their medication, and communicating their needs and concerns with health professionals. However, asymptomatic diseases like COAG are prone to poor patient adherence in following treatment plans (DiMatteo et al, 2002). A number of authors have suggested that the nature of COAG fosters non-adherence, with minimal chances of maintaining eyesight among patients who adhere poorly to treatment (Stewart et al, 1993). Poor adherence not only leads to poor health outcomes, but also unnecessarily increases healthcare costs (Haynes et al, 2002).

Discussions of adherence often detract from the reality of patient independence in self-managing their condition (Gifford and Groessl, 2002). By focusing attention on the power held by health professionals, there is a risk of discouraging collaborative problem-solving that addresses patient motivation and barriers to the taking of medication (Steiner and Earnest, 2000).

Self-management and expert patient programmes

Self-management programmes for patients with COAG are rare. It is postulated here that learning from the experiences of patients with other chronic conditions who have been through an expert patient programme (EPP) can provide useful guidance in establishing a glaucoma self-management programme. The concept of patient self-management first emerged in the 1960s and 1970s as a method for finding better solutions to living with chronic illness. The first structured self-management programme was developed by Lorig and colleagues (1999). In this scheme, self-management is seen as an integral, even central, part of the system of care provided to people with chronic diseases (Department of Health (DH), 1999). This approach to the management of chronic disease, or long-term conditions, has been taken up in many countries around the world, including Australia, China, South Africa, Canada, and many European countries, including the UK.

Based on Lorig's model, the DH established the Expert Patient Programme as a lay-person-led self-management programme designed specifically for people living with long-term conditions (DH, 1999). The aim of this programme is to support people by increasing their confidence, better managing their condition and subsequently improving their quality of life. The DH identified the most common chronic diseases that have a significant impact on a person's quality of life and on their family among the UK population. These are arthritis, asthma, back pain, diabetes mellitus, epilepsy, heart failure and multiple sclerosis (DH, 2002). Having been

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Adherence: compliance, persistence and concordance in the management of glaucoma. Part 1

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 recognize 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 2 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.

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Adherence is a term that is frequently discussed by healthcare practitioners in relation to patients managing their health. It is recognized 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 recognized 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 recognize 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 minimize the visual field loss by slowing the progression rate of the disease in individuals with elevated 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 IOP and should be used with caution in patients that have glaucoma. However the effect of organic nitrates and nitrites on IOP has been found to be variable and 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

Adherence: compliance, persistence and concordance in the management of glaucoma. Part 2

Abstract

Adherence was noted in Part I of this series as a concept laden with difficulties in relation to the management of glaucoma. A significant issue associated with a lack of adherence is the patient's failure to recognize there is a need to administer their eye drops as prescribed. Part I identified that 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. It was further noted that understanding the complexities of adherence and its association with persistence, compliance and concordance can assist the healthcare practitioner in developing models of care that help the patient in self management of their glaucoma. This article addresses the theory of adherence and self management of chronic open angle glaucoma and discusses perspectives, theories and models that help the patient in self management of their glaucoma.

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As noted in the previous article, *Adherence: Compliance, Persistence and Concordance in the Management of Glaucoma, Part 1*, adherence is a term that is frequently discussed by healthcare practitioners in relation to patients managing their health (Amro and Cox, 2011). It was further noted that it is recognized 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. A significant problem associated with adherence is the patient's failure to recognize there is a need to administer eye drops as prescribed. This is associated with the fact 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 theory of adherence and self management of chronic open angle glaucoma (COAG) and discusses perspectives, theories and models that help the patient in self management of their glaucoma.

Theory of adherence and self management of COAG

Theories are essential in promoting an understanding of human behaviour, directing research and facilitating transferability from one health issue, geographical area or healthcare setting to another (Michie et al, 2005). However, early programmes related to self management of different chronic conditions frequently lack an explicit theoretical basis. The problem of adherence remains a challenge as it relates to human behaviour and self management of COAG.

Munro et al (2007) examined the empirical evidence and theories applied in changing behaviour interventions in relation to long-term disease self management and treatment regimen adherence. Their review revealed that certain theories have the potential to both improve understanding of behaviour change and contribute to the design of more effective interventions that promote collaborative partnerships and adherence. Several interventions have been designed to improve patients' treatment adherence, but few theories describe the processes involved in doing so (Michie et al, 2005; Olthoff et al, 2005). With more than 30 theories of health behaviour change available, choosing the most appropriate theory when designing an intervention is far from an easy task (Munro et al, 2007). This is particularly problematic in the field of adherence to long-term medications, such as medications required to manage COAG where the cost of non adherence is quite severe with an ultimate eye sight loss.

Leventhal and Cameron (1987) initially classified five theoretical perspectives (models) related to long-term treatment adherence: biomedical; behavioural; communication; cognitive; and self regulatory. Recently a sixth domain, stage perspective, has emerged. Each perspective (model) includes several theories, where the most commonly used theories are those within the cognitive perspective and the transtheoretical model of the perspective stage (Redding et al, 2000). Each of these perspectives will be reviewed in the narrative that follows.

Biomedical perspective

A patient in the biomedical perspective is viewed as a passive recipient of the doctors' instructions, where a patient who fails to adhere is understood to be caused by patient characteristics like age and gender (Blackwell, 1992). Technological innovations to monitor adherence to medications, such as the 'unobtrusive eye drops monitor' are rooted in this perspective.