Ocular Disease and Sight Loss: Meeting Psychosocial Needs

Susan Watkinson
Swapna Naskar Williamson
Editors

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Foreword

I am delighted and very honoured to write a Foreword for this publication which will be an extremely important and relevant text dealing with the psychosocial care of patients with ocular disease, sight loss, altered body image and associated stigma. The feelings of fear, anxiety, loneliness, depression and altered body image are real emotions often experienced by patients with ocular disease and sight loss. I believe this book fulfils its brief in raising the awareness of ophthalmic healthcare professionals and all allied healthcare practitioners about the importance and need to deliver psychosocial care to this vulnerable community of people who are losing sight due to ocular disease.

This text is comprehensive and includes a wide range of areas which have been presented in a logical and straightforward format. It is interesting and reader-friendly, enhanced by the use of case studies, illustrations and the lived experiences of patients with sight loss. It presents holistic, patient-centred care as a basis for achieving emotional recovery, patient empowerment, independence, psychosocial well-being and quality of life. Reading this text will allow healthcare professionals to share their knowledge nationally and internationally.

Currently, healthcare professionals are technology-driven because of the crucial role it plays in nursing. However, there is a great need for an intricate balance between art and science in nursing practice. The amalgamation of these two domains can result in the creation of a far more effective and dynamic caring approach to achieving optimal visual outcomes and quality of life.

All healthcare professionals, as members of an interdisciplinary team, should be educated to embrace the importance of psychosocial care as part of a holistic, patient-centred approach. The challenges of ocular disease, sight loss and altered body image are numerous for healthcare professionals to address. Thus, undergoing specialised advanced training will help healthcare professionals to provide patients with the necessary direction to achieve independence to live with and manage their ocular problems within their self-defined quality of life.

This book is a great resource which provides an intelligent and comprehensive platform. It is such a relief to see the emergence of a text which is long overdue in raising the awareness of healthcare practitioners and academics about the importance of embedding the knowledge and understanding of psychosocial care in their practice. The development of evidence-based ophthalmic practice within the domain of psychosocial care could be achieved by action research involving healthcare practitioners in the experience of collecting data related to the needs of patients with ocular disease and sight loss.

Debbie Ehlers
The Eye Center
Debbie Ehlers is also a past President
of ASORN (the American Society
of Ophthalmic Registered Nurses)
She led this organisation for many years
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Preface

This text discusses the psychosocial care of patients with ocular disease and sight loss and addresses the importance, relevance and application of psychosocial and nursing theories for treating and dealing with the implications of ocular disease on a daily basis thereby initiating a new way of thinking treatment. The role of the healthcare professional is viewed as one which helps with the experiences of living with ocular disease, facilitates emotional recovery and empowers individuals to regain independence to self-manage their ocular disease and re-establish quality of life.

Psychosocial care remains an extremely important part of the holistic approach to care, but one which has been underestimated in clinical practice and only superficially addressed in the ophthalmic literature to date. Ocular disease and sight loss are viewed mainly in the literature from a medical perspective focusing on treating the medical condition of individuals and not providing adequate emphasis on the post medical treatment of addressing the psychosocial needs to enable them to adapt to their condition.

Currently, a technology-enhanced approach to caring often dominates to the detriment of assessing the individual's psychosocial needs and providing appropriate care. Although the skills afforded by science and technology are important for healthcare professionals in practice, the impact of the transfer of such skills on patients can often trigger innermost feelings of fear, anxiety, stress, loss of control, and a sense of alienation. This text seeks to address the imbalance often observed between nursing both as an art and science. Most significantly, this text has been written to challenge all healthcare professionals to think about raising their awareness of the importance and the value of psychosocial and nursing theory as a basis for addressing this imbalance. This will consequently enable them to achieve holistic and comprehensive ophthalmic nursing practice.

Brentford, UK Susan Watkinson
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Contents

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She has considerable experience of teaching ophthalmic nursing, general nursing, research, and ethics and philosophy within pre- and-post-registration nurse education, and research methodology and applied research philosophies for postgraduate and PhD programmes. For the past several years, she has taught psychosocial theory and its application to ophthalmic practice for the BSc (Hons) Professional Practice (Ophthalmic Nursing) course at the University of West London.

Ophthalmic nursing remains her specialist clinical interest, and she has published extensively within nursing journals, contributed book chapters and had two ophthalmic nursing books published: *Issues in Ophthalmic Practice: Current and future challenges (2009)* and *Older People with Visual Impairment: Clinical management and care (2014).* Her current research interest focuses on exploring the emotional impact of sight loss and the associated psychosocial needs and care of patients with ocular disease.

Swapna Naskar Williamson, RN, RM, BA, BSc (Nursing), MSc (Nursing), LLB, MMEd, PhD is a Senior Fellow of the Higher Education Academy (HEA). Her 35 years of teaching experience in higher education from Level 4 to doctoral students includes learning skills development, service improvement, research methodology and ethics. As an Associate Professor at the College of Nursing, Midwifery and Healthcare, University of West London, she was actively engaged in and led in developing curriculum and documentation, counselling, teaching and assessing students of the Foundation Degree in Science and Health and Social Care, undergraduate and postgraduate, and PhD students. She is also associated with the All India Institute of Medical Sciences in the State of Jammu, North India.

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Susan Fowler is a past editor of *Insight*—the journal for ophthalmic nursing. She continues to write for the EyeKnow newsletter for the American Society of Ophthalmic Registered Nurses (ASORN). She disseminates her research findings in a variety of nursing journals.

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Chapter 1: Introduction

Susan Watkinson
and Swapna Naskar Williamson

1 Introduction

This book targets nurses and other allied healthcare professionals including optometrists, doctors, mental health nurses, counselors, psychologists, social care workers, and occupational therapists caring for patients with ocular disease and sight loss within hospital, clinic, and community settings. For the purpose of this text, nurses will be included in the generic term "healthcare professionals," which will be used throughout. The main aims of the book are, firstly, to discuss the need for a theoretical basis for nursing care to improve patient care with reference to the emotional needs and psychosocial care of patients with ocular disease and sight loss. Secondly, it aims to raise awareness of the importance and relevance of the psychosocial aspects of care for ophthalmic practice with reference to psychosocial theory and its application. Thirdly, It will also discuss the role of healthcare pro-

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Table 1 Definitions of key terms and concepts

Key terms and concepts	Definitions and explanations
1. Psychosocial care	Psychosocial care consists of providing holistic care, spiritual care, support to the patient and family members, and showing empathy. It is about communication between nurses and the patient and family members as well as communication among nurses. It involves collaboration between healthcare professionals and multidisciplinary care [1].
2. Well-being	Is a broad concept and described as relating to personal dignity, an individual's control over daily life, participation in work, education, training or recreation, social and economic well-being, domestic, family, and personal well-being, suitability of living accommodation, and the individual's contribution to society [2]. Specifically, psychological well-being is about the combination of feeling good (emotional health) and functioning effectively [3].
3. Emotional distress	Emotional, or psychological distress is when an individual becomes overwhelmed by his or her own emotions and thoughts. It can present as depression, anxiety, or panic. Counsellors, therapists, and other specialists can be helpful to patients in emotional distress.
4. Holistic care	Refers to the provision of care to patients that are based on a mutual understanding of their physical, psychological, emotional, and spiritual dimensions [4].
5. Therapeutic communication	Is a way of connecting with patients and building face-to-face interpersonal relationships through empathy and listening skills and a process of information transmission. It is a significant tool in patient-centered care [5].
6. Multi-disciplinary team concept	This is a diverse group of professionals working together to deliver person-centered and coordinated care and support for a person with care needs. Through accessing a range of health, social care, and other community services, MDTs focus on keeping people well and independent by delivering appropriate care at home or in the community [6].

fessionals as part of a multidisciplinary team to help provide integrated care. This holistic approach helps facilitate care to relieve emotional distress and promote quality of life for patients with ocular disease and sight loss.

First, definitions/explanation of some key terms and concepts used throughout this text will be provided as a reference for the reader's understanding of their meaning (see Table 1).

2 Background

Ocular disease represents a significant change in the overall health of individuals, especially where there is the possibility of sight loss, or where sight loss has already developed. Sight loss can give rise to emotional reactions and numerous psychosocial problems, which have to be addressed in order to help and support individuals to maintain their quality of life. This requires a holistic caring approach to addressing these problems from a culturally integrated perspective.

2.1 The Eyes as Sensory Organs

The eyes may be viewed as the most important of all the human sensory organs allowing interaction with others and continuous contact with the immediate environment. Human eyes are unique in the process of communication and perception, and sight is important in the maintenance of self-esteem and the confidence to live an independent life [7]. It is crucial to recognize that sight is precious throughout life and its loss affects individuals in many ways resulting in depression, isolation, and suicidal feelings in extreme cases [8, 9]. There is a documented increased risk of suicide in visually impaired people [9], and suicidal ideation has been linked with sight loss in older people where the risk increases with the severity of loss [10, 11].

The eyes are the portal of entry through which information reaches the brain for interpretation and allows us to learn new things about the world and make sense of the environment around us. For people with visual impairment, the brain continues to seek out information as in the case of a sighted person converting information from many sources in a visual form [8]. Poor eyesight, however, can have negative effects on a person's physical well-being resulting in immobility, dependence, limited self-care ability, and difficulties in managing the activities of living; this eventually reduces the person's psychosocial well-being leading to depression, anxiety, poor communication, isolation, loneliness, helplessness, neglect, and loss of identity [7]. These negative effects of poor eyesight can nevertheless be managed by adopting a positive attitude toward self-care. The concept of self-care identifies individuals as having the ability to perform self-care and take responsibility for their own health and quality of care. According to Orem's self-care deficit nursing theory, developmental self-care requisites are associated with developmental processes; health deviation self-care is required in conditions of illness, injury, or disease [12]. The most relevant requisites with reference to sight loss would be, firstly, modifying self-concepts to accept oneself as being in a particular state of health and in specific forms of health care; secondly, learning to live with the effects of pathological conditions such as ocular disease and sight loss. Orem's theory, therefore, is relevant to all healthcare professionals contributing to the promotion of self-care for individuals with ocular disease and sight loss. Specifically, however, the self-care deficit nursing theory identifies five methods of nursing help, one of which is promoting personal development in relation to meeting future demands. This would be a process of empowering patients to re-establish independence in managing their own ocular condition [12].

3 Global Statistics

Blindness and visual impairment are global phenomena that affect society and individuals and have economic consequences. Increasing life expectancy and a continued rise in the global population coupled with poor access to health care in low-income countries contribute to the overall increase in numbers of blind and visually impaired people worldwide. It is estimated that given the current increases in the global population, the prevalence of vision loss will have risen from 7.8 billion in 2020 to 9.7 billion in 2050 [13]. In addition, epidemiological data have reported that globally there are at least 2.2 billion people diagnosed with a near or distance vision impairment, of which at least 1 billion cases could have been prevented or are yet to be addressed [14, 15]. These cases include people with moderate or severe distance vision impairment or blindness due to unaddressed refractive error (88.4

million), cataracts (94 million), glaucoma (7.7 million), corneal opacities (4.2 million), diabetic retinopathy (3.9 million), and trachoma (two million), as well as near vision impairment caused by unaddressed presbyopia (826 million) [13]. The majority of people with visual impairment and blindness are over the age of 50 years; however, vision loss can affect people of all age groups [13].

4 Psychosocial and Holistic Care Needs

Visual impairment is a disability that affects the physical, physiological, and psychosocial aspects of an individual's well-being. Patients with visual impairment and blindness often report their concerns about the physical and functional deficits. A majority of ophthalmic patients adjust positively to their own disabilities; however, identifying the strategies that are associated with a successful adaptation and an appropriate system of psychosocial support can be put in place to help those who are adversely affected [16]. Psychosocial care is the culturally sensitive provision of psychological, social, and spiritual care through therapeutic communication. Current evidence suggests that effective psychosocial care improves patients' health outcomes and quality of life [1]. Psychosocial care remains an extremely important part of the holistic approach to care, but one which has been underestimated and under-researched in ophthalmic clinical practice. The impact of being underestimated over a long period of time has not improved patients' levels of satisfaction and feelings of benefit following treatment for ocular disease and sight loss. One study concluded that a significant proportion of patients with visible disfigurement due to ocular disease experienced high levels of psychosocial distress and were less positive in their ratings of care provision to meet their needs [17]. Holistic care provides an in-depth understanding of patients and their comprehensive care needs and is at the heart of the science of nursing. Holistic care can and should also contribute to patients' satisfaction with their healthcare, thus helping them to accept and assume self-responsibility. Psychosocial alongside ocular needs should therefore be responded to within a holistic caring paradigm [4, 18].

4.1 Barriers to the Provision of Psychosocial Care

Qualitative research evidence suggests that nurses' perceptions of barriers to providing psychosocial care include lack of time, language barriers, being task-orientated, excessive documentation, lack of family involvement, and fear of complaints [1].

Furthermore, psychosocial care often gets less attention from healthcare professionals due to the dominance of a technology-enhanced approach to caring practice. Clearly, the knowledge and skills afforded by science and technology are important for healthcare professionals in practice, but it is also important for them to be aware of the impact of the transfer of such skills on patients with ocular disease from a humanistic perspective. The delivery of technology-enhanced care can often trigger innermost feelings and needs such as fear, anxiety, stress, loss of control, and a sense of alienation. This book seeks to address the imbalance often observed between nursing both as an art and science and to emphasize the importance of raising the healthcare professionals' knowledge and understanding of the value of social psychology and its application to ophthalmic practice in addressing this imbalance.

4.2 Establishing Well-Being

Vision loss can be a traumatic life event, and the care of patients experiencing such loss requires attention to individual needs that extend beyond the immediate ocular concerns [19]. One of the most important psychosocial needs is to establish a sense of well-being. For the patient with glaucoma, for example, the prospect of long-term visual disability, lifelong medical and surgical treatments, and the knowledge of having an irreversible potentially blinding condition tend to cause severe psychological stress leading to anxiety or depression. The goal of glaucoma treatment therefore should not be limited to preserving the vision but should also address the psychosocial aspects of care and preservation of patient well-being. To this end, patient counseling following diagnosis, ongoing periodic psychological assessment, and creating awareness in society as a whole should be implemented as part of a holistic approach to patients with glaucoma [19].

Individual patient needs should also be considered with reference to different age groups. Evaluation of the effects of profound vision loss on the psychological well-being in adolescents, young adults, and middle-aged adults with reference to mood, interpersonal interactions, and career-related goals found that the majority experienced significant psychological morbidity. Approximately 50% became clinically depressed, and many reported profound negative effects on their interpersonal interactions and career goals [20].

5 Outline of Chapters

1. Chapter 2: "The Value of Applying Psychosocial Theory and Models to Ocular Disease" focuses on the importance of the concept of theory having its basis in philosophy, which itself looks at the problems affecting human thinking and behavior.

   Some nursing theories and models such as Roy's Adaptation Model and Orem's Self-Care Model alongside psychosocial theories such as Bandura's Social Learning Theory, Lazarus and Folkman's transactional theory of stress and coping, and Pender's Health Promotion Model, based on expectancy and social cognitive theory, are selected and discussed to demonstrate the need for a theoretical basis both for general nursing practice and the specialist area of ophthalmic practice. The integration of these theories is important for healthcare professionals in helping them to meet the psychosocial needs of patients with general health conditions and the specific psychosocial needs of patients with ocular disease and sight loss.

   In addition, Walker and Avant's seven steps of theory analysis are described to demonstrate the appropriateness of using such theories and models in practice. The value of applying them to meet both the needs of patients in general nursing and the specific psychosocial needs of patients with ocular disease and sight loss is subsequently shown through the presentation and examination of case scenarios. Examples are drawn from a range of health conditions that can equally be applied both to general nursing as well as specific ophthalmic nursing. Application of theory to practice is reinforced by examples from published research evidence from clinical studies undertaken.

Importantly, this chapter concludes with future directions that herald significant messages for healthcare professionals about the importance of the link between theory, research, and practice as a means of professional knowledge and practice development.

2. Chapter 3: "The Psychosocial Impact of Ocular Disease on Body Image" explores the concept of altered body image due to ocular disease and the importance of psychosocial care in meeting individual needs within a holistic framework. Body image as a concept is defined, and some ocular conditions are described where body image is a psychosocial issue. Ocular conditions addressed include exenteration of the orbit for an ocular tumor, strabismus (squint), thyroid eye disease, and herpes zoster ophthalmicus.

   The psychosocial impact of disfiguring ocular disease can have a profound effect on quality of life [21] resulting in anxiety, clinical depression, distress, and social avoidance. This chapter focuses on body image with reference to Price's Body Image Model [22]. This model has been used to characterize the difficulties encountered by patients who experience body change as a result of illness, injury, or disability. It remains a challenge, however, for nurses to establish care plans that can assist patients in managing the psychological adjustments associated with disfigurement. Body image rehabilitation may take a prolonged period of time, and it is essential for healthcare professionals to understand what the patient is thinking and feeling throughout the rehabilitation process and which stage of change the patient is working through [23]. Thus, the need for establishing therapeutic communication with patients is instrumental in restoring self-esteem and confidence and facilitating empowerment toward self-management of their rehabilitation back into society.

3. Chapter 4: "Stigma Related to Sight Loss and Psychosocial Care". The psychosocial implications for patients with ocular disease and sight loss are considered in a detailed discussion around the concepts of stigma, stereotyping, and labeling. There is a focus on the stigma associated with ocular disease and sight loss, its psychosocial effects, and healthcare approaches needed to address the issues and challenges. The attitudes and behaviors of the general population and healthcare professionals toward people who are blind or visually impaired are explored, and the psychosocial barriers are outlined. Stereotyping is a barrier to the social participation of older adults with low vision. Study findings highlight that stigma in the environment perceived or experienced is a critical factor to address for older people with low vision as it has the potential to reduce social participation and, in some cases, diminish help-seeking and ultimately impact health [24].

   The psychosocial effects of stigma on people who are blind from birth or who have developed sight loss in later life are also described. The psychosocial role of healthcare professionals is discussed with reference to supporting blind or partially sighted people and their families experiencing stereotyping. It concludes that raising social and professional awareness of the psychosocial needs of people with blindness or partial sight is vitally important in reducing labeling.

4. Chapter 5: "Living with Ocular Disease and Quality of Life" focuses on the emotional reactions of sight loss and their impact on the experiences of living with ocular disease and quality of life. In this chapter, the ocular diseases selected for discussion with reference to current published clinical evidence are cataract, primary open-angle glaucoma, and age-related macular degeneration because they affect not only the physical abilities of patients but also their psychological sense of well-being. In particular, the more challenging aspects of

psychosocial care associated with Charles Bonnet Syndrome and depression require the healthcare professional to apply more knowledge and skills to address the specific psychosocial needs of patients to ensure their return to some degree of quality of life [25, 26]. Psychosocial care, effective communication, health education, good interpersonal skills, and counseling skills, including lifestyle counseling, are essential aspects of the healthcare professional's role in identifying individual patient needs and providing appropriate person-centered psychosocial help and support for self-empowerment and self-management of their ocular condition.

The prospect of sight loss and going blind is daunting, and therefore developing a therapeutic relationship with the patient is essential. The healthcare professional should strive to gain insight into the patient's feelings and fears around blindness.

Developing the use of effective counseling skills is therefore essential; active listening and positive responses are needed to achieve this. Patients are then better able to cope with their emotions. Thus, providing sufficient time to spend with patients to allay their apprehensions and fears is fundamental to achieving the desired benefits of counseling to restore confidence and facilitate self-empowerment during rehabilitation [27].

5. Chapter 6: "Conclusion"
   This chapter presents a summary of the text by returning to the main aims and revisiting the key issues addressed in each chapter. In drawing some conclusions from the chapter discussions, it presents future perspectives on the significance of psychosocial care for patients with ocular disease and sight loss within the holistic paradigm. It further presents some future perspectives on the role of the healthcare professional in providing psychosocial care for patients with ocular disease and sight loss to achieve recovery from emotional distress and re-establish independence as a basis for self-empowerment and future control in the management of their ocular condition. It is important to encourage nurses to participate in research in their area of practice and share experiences to improve patient care with particular reference to psychosocial care issues.

They may not conduct primary research themselves, but they can become involved by contributing to research activities within a designated professional researcher-led team. Action research, for example, would be a crucial means of allowing healthcare professionals to participate in the experience of collecting data based on meeting the psychosocial needs of patients with ocular disease and sight loss. This would represent a positive approach toward developing evidence-based practice within the domain of ophthalmic psychosocial care. Action research must be seen as a building block for healthcare professionals to become involved and contribute toward participating in clinical research in practice to generate evidence to improve it. It is also the basis for introducing and utilizing the philosophy of the psychosocial aspects of ophthalmic practice.

Healthcare professionals should be able to raise their awareness of the key issues presented and the clinical evidence arising from research and relevant literature for the continuing development of healthcare with particular reference to the psychosocial aspects of caring for patients with ocular disease and sight loss.

To conclude, this introductory chapter has provided the reader with an overview of some of the key issues surrounding the area of meeting the psychosocial needs of patients with ocular disease and sight loss and providing the appropriate psychosocial care within a holistic framework. It has also given an outline of the chapters being presented and the specific topics under discussion.

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Chapter 2: The Value of Applying Psychosocial Theory and Models to Ocular Disease

Susan Fowler

1 Introduction

Theories and models of care are important and need to be used to understand and explain the health behavior of people to enable the identification, development, and implementation of care interventions. Eye conditions, for example, ptosis, disfigurement of the eye, and altered vision, can result in negative psychosocial impact and affect the patient's overall satisfaction and outcomes, despite successful medical and surgical interventions. Healthcare professionals attending to ophthalmic patients and their family members need to provide comprehensive care incorporating physical, psychosocial, emotional, and spiritual dimensions of care throughout the course of assessment, treatment, and evaluation of care to optimize outcomes and enhance the quality of life. It is paramount that healthcare professionals are knowledgeable

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and competent to recognize the value of applying psychosocial theories and models to ophthalmic conditions and related investigations and therapeutic interventions. Basic understanding of theory and conceptual models will lay the foundation for understanding and appreciating psychosocial theories and models and their appropriate application to ensure patient safety and quality of care, thereby achieving healthcare outcomes. Nurses can play a key role in the integrated person-centered holistic care approach by facilitating the coordination of activities among all members of the multidisciplinary healthcare team. This can be achieved through collaboration and partnership working in order to enhance the quality of patient care [1, 2].

This chapter will present an overview of theory with a focus on specific theories applicable to ophthalmic nursing practice. A major focus of the nursing care of individuals with ocular disease is the psychosocial response to altered vision. Adaptation, self-care, social learning, coping, and health promotion are addressed by nurses when providing psychosocial support. As a result, five theories focusing on these concepts were selected for review in this chapter.

2 Background

2.1 Theory

Theory is made up of concepts and statements, including relationships between concepts that describe a systematic view of a phenomenon [3]. A phenomenon is a happening, idea, or concept such as coping, health promotion, or self-care. Theory is based on philosophy. Philosophy looks at problems that affect human thinking and behavior. Philosophy seeks to discover knowledge and truth, identifying what is valuable and important [4]. For example, philosophy can explain the value of self-care when it comes to managing diabetes and the development of diabetic retinopathy. Nursing theories address four meta-paradigms that outline the foci of the profession including (1) person, (2) health, (3) environment, and (4) nursing.

Theory can be used to guide practice in clinical, managerial, administrative, education, and research arenas. In clinical practice, a theory can provide an organizing framework to patient care. A nurse caring for a patient with sudden blindness, due to a traumatic injury, in the acute rehabilitation setting, who uses an environmental theory such as Florence Nightingale, will focus on safety and positive contributions of the environment. In another example, the nurse educator (nursing), teaching second-year baccalaureate nursing students (person), in the ambulatory ophthalmic surgical suite (environment), uses a learning theory to assist nursing students in becoming more independent in the application of their critical thinking skills (health) in detecting surgical complications.

2.2 Seven Steps of Theory

The analysis and application of theory can be approached using the seven steps of theory analysis suggested by Walker and Avant [5] including:

- Origins.
- Meaning—major concepts and how concepts relate to each other.
- Logical adequacy—is the structure of the theory and the statements logical?
- Usefulness—is the theory practical? Can it guide practice?
- Generalizability or transferability – can we make generalizations based on the theory—can it be widely applied or is it limited?
- Parsimony—can you simply describe the theory despite its complexity or completeness?
- Testability—can the theory be tested in a study and empirical evidence gained about it and its use?

This approach using some or all the steps helps determine the strengths and weaknesses of a theory and its potential use in practice. Two nursing theories and two non-nursing theories will be discussed, highlighting their use in ophthalmic nursing practice.

3 Roy's Adaptation Model

3.1 Origins

Sister Callista Roy first began developing the Roy Adaptation Model while studying for a master's degree when a professor challenged her students to develop conceptual models of nursing. Roy's proposed model came from Dorothy Johnson's own behavioral system model of nursing, which focuses on the patient as one behavioral system consisting of seven subsystems.

3.2 Meaning

Concepts of the Roy Adaptation Model include environment, health, person, goal of nursing, adoption, focal stimuli, contextual stimuli, presidential stimuli, cognitive subsystem, regulatory subsystem, stabilizer control processes, and innovator control process use [6]. The Roy Adaption Model focuses on coping processes and the interrelatedness of four adaptive systems: physiological, self-concept/group identity, interdependence, and role function. The individual is viewed in this theory as an adaptive being. The environment includes all factors that affect the individual, including health status and any conditions that affect the individual. Health is a dynamic state. Nursing serves to promote the wholeness of the individual.

3.3 Logical Adequacy

Concepts are interrelated. The individual is affected by the three other concepts in either a negative or positive way based on whether or not there are alterations in the other concepts.

3.4 Usefulness

The usefulness of this model has been used extensively to guide practice and organized education in multiple nursing programs. The logical adequacy of RAM provides us with the ability to make predictions. If we think about a homeless person, we can predict that the environment will have a negative effect on the individual and his/her health. Nursing will focus on helping return the individual to a state of health with limitations of resources.

3.5 Generalizability

The Roy Adaptation Model is very generalizable as evidenced by its ability to be applied to not only individuals but also communities and populations. Life is a continuous phase of adaptation with humans as dynamic beings, and therefore, the application of the theory can be generalizable.

3.6 Parsimony

This model may not be parsimonious because it contains many elements, system structures, and concepts, although it has been noted to be practical [7] and applied to practice [8].

3.7 Testability

The Roy Adaption Model is testable, as demonstrated in over 150 studies using the model with an international nursing society dedicated to research on adaptation and nursing identified as the Roy Adaptation Association. RAM has since served as the basis for other theories and concepts.

3.8 Report of Utilization of Theory in Research and/or Practice

Kilic et al. [9] used Roy's adaptation model to guide a six-part educational intervention about hypertension and its management in a randomized controlled trial. There was a significant difference between pre- and post-test scores related to adaptation and blood pressure in both the experimental ($N = 75$) and control ($N = 80$) groups, but only statistically different ($p < 0.001$) in the experimental group.

3.9 Application to Ophthalmic Nursing Practice

Mrs. Smith is a 60-year-old housewife who noticed decreased vision in her left eye but decided these changes were simply a result of "old age." Her medical history includes hypertension and hypothyroidism. When her vision started to change in her right eye, she sought medical assistance. She was diagnosed with age-related macular degeneration. Mrs. Smith was given an eye chart to keep track of how her eyes were doing and the detection of changes. She was also given a special dietary supplement (vitamins and minerals) that may lower the progression of the disease in her right eye. The ophthalmic registered nurse educated Mrs. Smith on these interventions using teach-back and return demonstration to ensure understanding and proper use of the eye chart and dietary supplements. Mrs. Smith adapted to physical changes to her health by ensuring daily monitoring of her vision and adherence to prescribed medications, using a magnifying glass to read labels and recipes when cooking, moving living room furniture closer to the television for better visibility, and ceasing driving an automobile with reliance on her husband for transportation to appointments and shopping. Her adaptation demonstrates the relationship between the four adaptive modes. The ophthalmic registered nurse must engage in therapeutic communication in order to understand Mrs. Smith's challenges and opportunities related to vision changes. The ophthalmic registered nurse promotes adaption in all four modes through assessment, evaluation, and support of her efforts to cope with vision changes so that she can maintain participation in daily activities and feel valued in contributing to the quality of life. Change can be difficult but requires adaptation in order for a person to move forward with acceptance and actions to maintain and strengthen a sense of well-being. The ophthalmic registered nurse alongside other healthcare professionals need to provide comprehensive care to ophthalmic patients and their family members. Moreover, it is important to reinforce that the role of all healthcare professionals is to contribute to improving practice outcomes through continuous observation and reflection.

4 Orem's Self-Care Deficit Nursing Theory

4.1 Origins

Orem's Self Care Deficit Nursing Theory found its origin from Parson and von Bertalamfy's structure of social action and systems theory [10].

4.2 Meaning

Orem's theory contains three interrelated theories of self-care, self-care deficit, and nursing systems. Self-care applies to oneself or others an individual depends on for care. An actual or potential self-care deficit needs nursing.

4.3 Logical Adequacy

The theory starts with the capabilities of an individual to care for themselves (self-care agency), followed by self-care needs, identification of self-care deficits, and involvement of nursing to promote life, health, and well-being.

4.4 Usefulness

Orem's theory often guides nursing practice since individuals, of all age groups, in our care have needs in which nurses address especially those related to caring for oneself across the continuum of care including community health, home care, emergency care, acute/critical care, ambulatory care, and rehabilitation.

4.5 Generalizability

Orem's theory can be widely applied to all age groups across all settings.

4.6 Parsimony

Each element of the theory has multiple layers making it somewhat complex but understandable. For example, nursing actions can be simply supportive or educative, partially address self-care needs, or completely compensate for the individual's inability to care for oneself.

4.7 Testability

Self-care is a universal concept and, therefore, can be tested through a variety of questionnaires or surveys. The surveys can address knowledge and/or skills such as management of diabetes to limit complications (e.g., Diabetes Self-Management Questionnaire).

4.8 Report of Utilization of Theory in Research and/or Practice

Gumbs [11] conducted a secondary analysis of a Centers for Disease Control data set examining factors to answer the following research question: What are the predictors of health-promoting self-care behaviors requiring visits to a healthcare provider of African American Women with type 2 diabetes among the basic conditioning factor variables of socioeconomic/sociocultural orientation, heath state system factors, and healthcare system factors? Socioeconomic/sociocultural orientation factors, such as age and employment, explained 4.2% of the variance, healthcare state factors accounted for 1.0% of variance, and healthcare system factors, such as health coverage, for 1.5% of the variance requiring visits to healthcare providers. Employment affects health, promoting self-care behaviors that align with healthcare provider visits.

4.9 Application to Ophthalmic Nursing Practice

Mr. Jones, 70 years of age, has had type 1 diabetes since he was diagnosed at age 10. Although the goal for his A1c has been 7%, he has struggled to achieve this level, challenged by eating and exercise behaviors. He was diagnosed with diabetic retinopathy 5 years ago and has undergone anti-VEGF treatments. Self-care agency applies to Mr. Jones' capabilities to care for himself including the management of his diabetes. His eyesight is limited as well as his hand dexterity due to arthritis signaling a self-care deficit. The ophthalmic registered nurse utilizes a multidisciplinary team approach and consults with the certified diabetic educator in the development of strategies for Mr. Jones to monitor his blood sugars and dietary intake and respond accordingly with subcutaneously administered insulin. Self-care agency also includes Mr. Jones' cognitive and emotional capabilities. The nurse and educator assess Mr. Jones' understanding and ability to manage his diabetes. He has been caring for himself and his diabetes for 60 years. Psychosocial care includes communication with Mr. Jones about his support system, relationships, and availability. If deficits are identified, the ophthalmic registered nurse collaborates with the healthcare team to address the physical, psychological, emotional, and spiritual dimensions of care.

5 Bandura's Social Learning Theory

5.1 Origins

Albert Bandura's social learning theory proposes that learning takes place in a social context with the interaction between the individual, environment, and behavior along with cognition that considers past experiences. Social learning theory formed the basis for Bandura's social cognitive theory.

5.2 Meaning

The theory suggests that learning is dynamic and interactive. We learn from others by observing, assimilating, and imitating them when we conclude that these experiences are positive. We learn without being aware of learning when we experience an ongoing barrage of stimuli [12].

5.3 Logic

Personal factors such as cognition influence behavior, which further influences the environment, and the cycle repeats itself in both directions. Furthermore, theory suggests that we learn by first observing, followed by imitating and modeling. This process does not happen without attention, retention of the behavior, replication of the behavior, and motivation to show what we have learned.

5.4 Usefulness

The theory can be applied to how patients and families learn as well as nurses and nursing students. The social nature of the theory makes it useful when examining learning and environments where learning takes place, such as the classroom, simulation lab, home, hospital, or clinic settings.

5.5 Generalizability

The theory has been useful in the development of educational interventions both for patients/clients and families, and nurses.

5.6 Parsimony

The theory provides a simple explanation of learning, taking into account the individual and environment, including school, clinical, work, and social environments but does not consider the influence of other factors such as biological predispositions.

5.7 Testability

Bandura's theory has been tested utilizing self-efficacy and motivation of individuals as it relates to learning across various disciplines. For example, the General Self-Efficacy Scale or GSES is used to assess perceived self-efficacy as it pertains to adaptation abilities and coping scales for both stressful events and daily activities.

5.8 Report of Utilization of Theory in Research and/or Practice

Bracken and Waite [13] studied the frequency of use of mobile applications (apps) (MyFitness Pal) in achieving health-related goals in 112 adults ages 18–59 years, based on Bandura's social cognitive theory focusing on self-efficacy for healthy eating. Higher levels of self-efficacy related to healthy eating and more frequent use of the app predicted greater goal achievement.

5.9 Application to Ophthalmic Nursing Practice

Mrs. Roberts, an 82-year-old woman, experienced a severe headache with tenderness over her right temple. She complained of scalp tenderness. When she suddenly lost vision in her right eye, she sought medical attention, but her vision loss was permanent. She was diagnosed with temporal arteritis and prescribed long-term steroids. She was an only child and grew up in a rural community with limited friends. She continues to live alone in the same house she grew up in. Mrs. Roberts' parents were her role model who demonstrated a self-sufficient, survival coping strategy that she has adopted. She does acknowledge some anxiety and depression related to social isolation and loss of vision impacting daily living. The ophthalmic nurse is concerned about her safety at home since she has acknowledged falling and sustaining injury. Within the context of the multidisciplinary team, the nurse makes a home health referral and puts Mrs. Roberts in touch with a low vision support group where she can call into the meetings using a mobile app to learn how others cope with vision loss and role model safe adaptation. Mrs. Roberts has the potential to establish relationships with others facing similar challenges with vision through the support group. Enhanced social well-being may overcome her anxiety and depression.

6 Lazarus and Folkman's Transactional Stress Theory

6.1 Origins

Richard Lazarus developed the transactional theory of stress and coping to explain stress as a dynamic process building on stress as a response outlined by Selye in the 1950s. In the 1980s, Lazarus and Folkman published their seminal work in the 1984 book titled *Stress, appraisal, and coping.*

6.2 Meaning

Lazarus' theory focuses on psychological responses to stress. Within the model, problem-focused and/or emotion-focused coping are part of the process of coping. Following one's appraisal of the stressful event, the individual will utilize either problem-focused or emotion-focused coping.

6.3 Logical Adequacy

Person–environment relationships, such as personality, values, beliefs, and support groups, and appraisals (primary, secondary, and reappraisal) precede stress and subsequently influence coping [14].

6.4 Usefulness

Stress and coping are universal across all ages and situations. The theory of stress forms the basis for some nursing theories such as Roy's Adaptation Model.

6.5 Generalizability

The stress coping theory can be applied to patients, families, and nurses. It is highly applicable to everyone's coping with the stress of the COVID-19 pandemic.

6.6 Parsimony

The two main concepts of stress and coping are easily defined with some variability depending on the individual and situation. For example, a new mother with her first newborn experiencing colic may describe stress and coping somewhat differently than the 70-year-old wife who is caring for her husband with advancing dementia.

6.7 Testability

Both stress and coping can be measured. For example, the Perceived Stress Scale (PSS) is a survey to measure perceived stress, and the Ways of Coping Questionnaire determines copying styles of problem-focused, emotion-focused, and mixed.

6.8 Report of Utilization of Theory in Research and/or Practice

Trougakos et al. [15] developed a conceptual model and path analysis starting with COVID-19 anxiety, the influence of hand washing frequency (problem-focused coping), emotions and psychological needs, and outcomes of progress toward goals, family engagement, and somatic complaints, integrating Lazarus and Folkman's transactional stress theory. Results from a study of 503 employees during the first 4 weeks of stay-at-home orders and social distancing indicated that COVID-19 anxiety impairs goals, home, and health outcomes due to suppressed emotions and lack of met psychological needs.

6.9 Application to Ophthalmic Nursing Practice

Mr. Rogers, a 65-year-old male, suffered a posterior circulation stroke resulting in cortical blindness, a gait disturbance, and difficulty swallowing. He was admitted to acute rehabilitation to maximize his functional abilities and adapt to ongoing deficits. After 3 weeks he gained strength and steadiness in mobility and subscribed to a modified diet with protective swallowing techniques. He continued to be angry about his vision loss and yearned for sight to see his grandchildren. This motivation led him to seek involvement in research opportunities. The ophthalmic registered nurse assessed Mr. Rogers coping and determined he was a problem-solver, and reappraisal of his altered health after identifying potential participation in a clinical trial resulted in his proactive actions. Prior to this stressful event of a stroke, Mr. Rogers had positive person-environmental factors including an outgoing personality, commitment to his family, and social support of his wife and family. Throughout participation in the clinical trial, the ophthalmic nurse continued to reassess and evaluate the success of his coping in terms of adaptation related to his physical health, psychological well-being, and social functioning.

7 Pender's Health Promotion Model

7.1 Origins

Pender's Health Promotion Model (HPM) was developed from the expectancy and social cognitive theory [16]. It focuses on behavioral aspects and factors that motivate behaviors as they relate to health promotion.

7.2 Meaning

The main concepts of the theory are individual characteristics, behavior-specific cognitions and affect, and behavioral outcomes [16].

7.3 Logical Adequacy

The theory logically flows from prior related behaviors and personal factors (i.e., biological, psychological, and sociocultural) that influence behavior-specific cognitions and affect (i.e., perceived self-efficacy, interpersonal influences of peers) to behavioral outcomes (i.e., commitment to a plan of action and health-promoting behaviors).

7.4 Usefulness

The HPM can be used to improve self-care in diverse populations including cultures and age groups.

7.5 Generalizability

The HPM comprehensively addresses variables that influence individuals taking action and engaging in health-promoting behaviors and, as such, can widely be applied including predicting behaviors.

7.6 Parsimony

The theory includes complex human phenomena about perception and a variety of interpersonal and situational influences limiting its simplicity and brevity.

7.7 Testability

The HPM model has been empirically tested with instruments including the Health Promoting Lifestyle Profile Instrument, the revised version of the tool, the Health Promotion Lifestyle Profile II (HPLP-II).

7.8 Report of Utilization of Theory in Research and/or Practice

Research of Tao and colleagues [17] on a nurse-supervised home exercise program in adults with renal disease requiring hemodialysis was guided by Pender's HPM. The design of the intervention was guided by six main variables from the model including perceived benefits of action, perceived barriers to action, perceived self-efficacy, activity-related affect, interpersonal influences, and commitment to a plan of action. The intervention group (N = 57), receiving an additional nurse-led individualized home exercise program and behavioral support during dialysis, reported significantly less barriers and higher levels of exercise than the control group (N = 56).

7.9 Application to Ophthalmic Nursing Practice

James Frank, a 25-year-old male, lost vision as a result of chemical exposure at work. He also suffered second-degree burns to his face and neck. He is distressed about this inability to see and distraught about his future, especially his career. He was physically active before the accident and loved to run and play soccer. James recognizes that he will not be able to play soccer but wonders about running. The ophthalmic registered nurse provides emotional support during this initial clinic visit and is concerned about his psychological well-being but recognizes that his physical strength can positively influence his emotional strength. The nurse suggests psychological counseling to promote psychosocial health and shares stories about vision-impaired runners and information about track clubs committed to the blind or visually impaired. James communicates a positive, prospective attitude, breaking down barriers and supporting his self-efficacy.

8 Future Directions

There is a wide range of theories from numerous disciplines including nursing, social sciences, behavioral sciences, education, and biomedical sciences. There has been limited use of theory to guide ophthalmic nursing research, although nursing departments or agencies often subscribe to a nursing theory as part of their philosophy of care or nursing professional practice model to guide practice. Nurses can learn from published studies that use a theoretical framework connecting the theory with study aims, data collection and analysis, and interpretation of findings. Incorporating theory into their research investigations, evidence-based practice projects, and/or quality improvement activities can strengthen and build nursing knowledge including theories themselves. Moreover, it is important to reinforce that the role of nurses and other allied healthcare professionals must contribute to improving practice outcomes through the process of ongoing reflection and critical evaluation. The ultimate goal will be the formation of an international ophthalmic nursing research collaborative with a theoretical foundation that has the potential to advance the science of ophthalmic nursing. This will also represent a major achievement in bridging the theory–practice gap.

9 Conclusion

Theory is linked to a philosophy about the world and the behaviors of its inhabitants. Using a standardized approach to analyze theories results in increased understanding of the depth and breadth of theories. Knowledge gained from the analysis of theories can be applied to the care of individuals with ocular disease, emphasizing psychosocial health. Increased application of theory to ophthalmic nursing practice will enhance its scholarly foundation. Most significantly, the application of theory to psychosocial care will enhance the holistic approach to ophthalmic practice.

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Chapter 3: The Psychosocial Impact of Ocular Disease on Body Image

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1 Introduction

The eyes are the most important sensory organs that are used for communication and social interaction. Ocular diseases that alter facial appearance can affect body image and have a negative psychosocial impact posing significant challenges to an individual. The visible eye disfigurements or any alteration surrounding the eyes that affect the normal appearance or body image of an individual have interpersonal and intra-personal consequences, which can also be stigmatizing. These patients may become self-conscious about their appearance and encounter challenges in finding ways to adjust to live with their eye disfigurement compounded with managing potentially negative reactions from others. Consequently, they not only have to adapt to the physical alteration associated with their eye disease but may also experience a significant psychological impact ranging from lack of con-

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fidence, low self-esteem, negative core beliefs about the self-appearance, and, in some cases, clinical levels of depression, anxiety, and distress affecting their quality of life [1].

This chapter focuses on the psychosocial impact of altering body image on patients with ocular disease and the role of healthcare professionals in providing psychosocial care and support to these patients and their families.

2 Body Image

Body image (BI) is a multidimensional construct that involves a person's positive and negative perceptions, thoughts, behaviors, and attitudes about their own body and appearance [2, 3]. BI is a mental representation of one's body that everyone develops irrespective of sex, age, and ethnicity of an individual throughout the lifespan. The development of BI is a dynamic process, which is influenced by the physical characteristics, e.g., body size or shape; psychological characteristics, e.g., perfectionism, low self-esteem, of the individual; and also by the socio-cultural context, e.g., cultural ideal of beauty and media pressure to achieve an ideal of beauty [4, 5]. For example, women celebrities have been found continuously under pressure to alter and maintain their physical appearance in response to media messages about body image. However, if their physical appearance worsens, it may affect their social interaction and relationship impacting on their self-esteem and confidence. This may make women feel embarrassed about their bodies leading to self-consciousness, stress, and anxiety [6]. Furthermore, BI is linked to the multifaceted psychological experience of embodying one's body. Thus, BI is not only related to the way people perceive their body, but it also influences the way they interact, engage, and communicate with society through the body as a whole. BI is a mental picture of how the self is perceived by others, how we would like to have ourselves seen, and that if you look good, you feel good [7].

BI encompasses (1) a behavioral component involving body-related behaviors, e.g., checking behaviors, (2) a perceptual component involving the perception of body characteristics, e.g., estimation of one's body size or weight, and (3) a cognitive-affective component involving cognitions, attitudes, and feelings toward one's body [8]. Appearance orientation is an overarching construct related to both the cognitive-affective and the behavioral component. It reflects the cognitive-behavioral aspect of one's appearance as an expression of the importance people place on their appearance. Thus, BI is a person's perception of their physical self and the thoughts and feelings, which can be positive, negative, or both. It is an individual's mental picture of one's own body as a whole that includes physical characteristics and one's attitudes toward these characteristics (American Psychological Association (APA). BI is "the subjective image one has of one's own body, with respect to evaluative judgements about how one is perceived by others and how well one is adjusted to these perceptions" [9]. It is influenced by internal and external factors, i.e., personality and social environment factors, respectively. Positive body image is important to develop self-esteem and confidence that contribute to the well-being of an individual to actively participate and interact in social activities. In contrary, negative body image due to any change in the appearance of the body may impose psychosocial challenges of an individual, thereby experiencing social isolation, loneliness, stereotype, and exclusion.

The face is an important part of the body, where any visible disfigurement of facial appearance, including eye conditions, alters a person's BI and leads to a range of potential psychosocial consequences for patients along with their medical treatments affecting their quality of life. BI is at the center of the way people see themselves and has been described as crucial to the development of self-concept [10]. Healthcare professionals must be aware of the ocular conditions leading to altered body image and the psychosocial difficulties patients may encounter so as to implement appropriate care models to improve the quality of life. It is therefore essential to see how a threat to a person's BI due to disfigured eye conditions also threatens his or her psychological well-being.

3 Ocular Conditions with Altered Body Image

The face is a major component of body image and self-worth. Individuals with normal and attractive facial appearance have many social advantages and are perceived as more popular, assertive, and self-confident. Any facial disfigurement due to ocular disease, whether congenital or acquired, has profound psychosocial implications including altered body image and reduced quality of life and self-esteem [11]. It affects how one is perceived and evaluated by others, guiding their impressions and behavior. Visible facial disfigurement due to ocular disease has negative effects on well-being such as lowered self-esteem, depression, and anxiety and can experience unfavorable reactions from others such as staring, unwanted questions, and avoidance [12]. There is a range of eye conditions that may alter body image affecting the psychosocial health of individuals. A summary of the common eye conditions altering body image has been presented below for a better understanding of their specific impact.

3.1 Losing an Eye

Losing an eye can be due to trauma, and malignant and nonmalignant conditions followed by surgical interventions such as enucleation, evisceration, and exenteration.

Exenteration of the orbit is shown in Fig. 1a. It is a disfiguring procedure that typically involves removal of the entire contents of the orbit including the periorbita, appendages, eyelids, and sometimes a varying amount of surrounding skin [13]. This intervention is carried out for the treatment of potentially life-threatening malignancies. Figure 1a shows after surgery the orbit has been left to granulate leaving a shallow depression with no prosthesis resulting in gross facial disfigurement. Patients may hide their deformities in various ways including dark glasses or head scarf extending over the face when in public. Patients often experience social problems and may find it embarrassing to interact with friends and family members. Some patients also experience

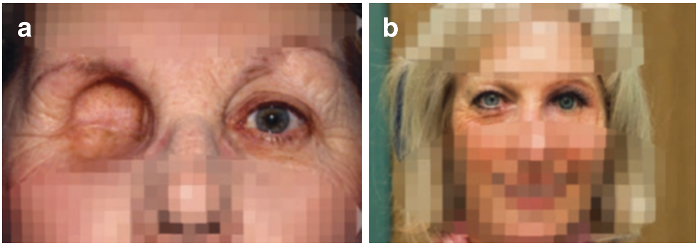

Fig. 1 (**a**) Exenteration of the orbit. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022. (**b**) Orbital prosthesis. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022

excessive interference with their lives from people offering unsolicited assistance. Additionally, patients do have a fear of the recurrence of cancer [13, 14].

Exenterations are performed mainly for malignant orbital and peri-orbital tumors. However, this procedure may also be performed in some benign (nonmalignant) orbital diseases for three main reasons: (1) to correct massive structural lesions, (2) to alleviate uncontrollable pain, and (3) to control extensive benign disease and tumors [15]. The majority of patients with benign disease can be treated by lid-sparing exenteration, with later fitting of an artificial eye. Aesthetic rehabilitation can otherwise be achieved by a suitable orbital prosthesis shown in Fig. 1b (of the right eye).

The use of a prosthetic eye can enhance a patient's confidence and self-esteem as it aims to improve the normal appearance and enhance positive self-image (Fig. 1b). Gaining the patient's trust and confidence is important as the patient may make several follow-up visits following surgery [16]. Patients may be advised to use broad rimmed spectacles, which are useful camouflage for the edge of orbital prostheses. However, for some, camouflage can bring its own problems in relation to issues of identity, over-reliance on the camouflaged image in social interaction, and fears that the "truth" will be discovered [17, 18]. Also, there is a lack of knowledge and clear understanding of psychosocial adjustment in those living with prosthetic restoration and coping with prosthesis. Self-esteem and self-image are the key components to interacting and influencing others [7]. Healthcare professionals must work together to provide psychosocial support to patients with disfiguring eye conditions so as to restore their self-esteem and confidence. Nurses are in a unique position to support them and their family members with appropriate training.

3.2 **Strabismus** (Fig. 2)

Strabismus, commonly known as squint, is the misalignment of a person's eyes. It has a significant negative psychosocial impact on patients, parents, and their children with strabismus. Both children and adults with strabismus often suffer from several psychosocial and emotional consequences such as poor self-image, negative social bias, ridicule at school, ostracization, depression, anger and outrage, increased social anxiety, poor interpersonal relationship, inhibition, and poor job opportunities in adults [19, 20].

Fig. 2 Strabismus. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022

3.3 Thyroid Eye Disease (Fig. 3)

Patients with thyroid eye disease are often distressed due to alterations in visual function which include red eyes, watery eyes, and pain. It also causes abnormal facial appearance which includes swelling of the eye lids, eyelid retraction and proptosis. They are stared at by others, feel embarrassed, experience distress in social situations resulting in limited social interaction leading to social isolation and altered sense of social identity [21].

3.4 Herpes Zoster Ophthalmicus (Fig. 4)

It is a debilitating condition caused by reactivation of the latent varicella-zoster virus characterized by conjunctivitis, epithelial keratitis, vesicular skin rash, and dermatitis with accompanying pain in the affected eye [22]. The physical and physiological health problems restrict patients' ability to continue normal daily and social activities affecting their psychosocial well-being. Patients with herpes zoster ophthalmicus experience

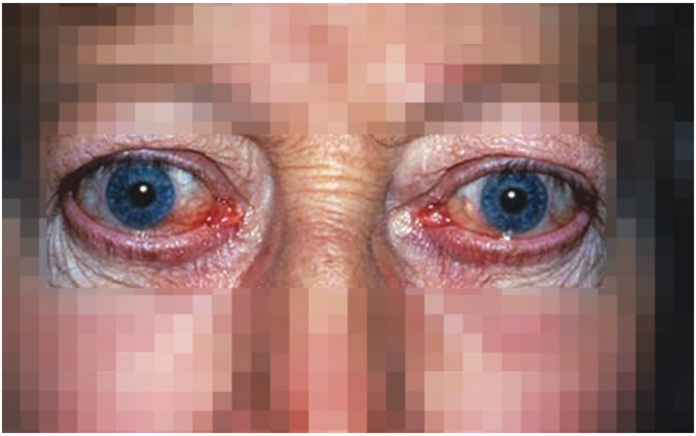

Fig. 3 Thyroid eye disease. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022

Fig. 4 Herpes zoster ophthalmicus. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022

embarrassment due to skin changes, anxiety, distress, fear of pain, and recurrence, leading to the loss of social contact, withdrawal and isolation, and reduced independence [1].

4 Psychosocial Impact of Disfiguring Eye Conditions Altering Body Image

Individuals with disfiguring eye conditions leading to altered body image experience a myriad of psychosocial challenges. Visible disfigurement is a social disability and it is associated with a range of psychosocial difficulties [23]. Individuals afflicted by facial disfigurement due to ocular conditions with body image disturbances experience physical and psychosocial challenges. It affects their eye health, appearance, and normal social functioning, thus imposing stress, anxiety, and depression. Any visible disfigurement of the facial structures such as eyes, nose, and mouth may result in increased susceptibility to distress [18]. Patients do express their concerns about the appearance of their eyes along with functional deficits. They are at risk of anxiety, stigma, discrimination, social isolation, and suicide [21, 11, 12]. Consequently, individuals with eye disfigurement become self-conscious and avoid going out in public as they feel embarrassed and anxious, so they withdraw from their friends and social activities, resulting in social isolation and spending more time alone.

People with visible facial disfigurement due to ocular disease are stressed and depressed. They are more at risk for BI concerns, lack of confidence, low self-esteem, and social interaction problems. These problems significantly contribute to developing negative self-perceptions and difficulties with social interaction. Consequently, patients with visible differences may develop negative emotions, e.g., social anxiety; maladaptive thought processes, e.g., fear of negative social evaluation; unfavorable self-perceptions, e.g., lowered self-esteem and unfavorable body image; and negative behavior patterns, e.g., excessive social avoidance, which may contribute to developing social and self-stigma (refer to Chap. 4 for further details).

An ethos of care needs to be developed in which appearance concerns can be discussed and the patient does not feel stigmatized by the offer of psychological support to deal with BI issues. Providing a supportive environment created by family members, friends, and healthcare professionals can help the person cope with their situations in maintaining their well-being (refer to Chap. 5 for further details).

5 Model of Care for Patients with Altered Body Image

5.1 Price's (2016) Body Image Model

Price's Body Image Model (Fig. 5) is a very helpful framework for the healthcare professional to use to assess the psychosocial needs of a patient with altered body image due to malignant and nonmalignant ocular disease, or injury, and then plan the psychosocial care required depending on the specific diagnosis. There are three essential elements within Price's Body Image Model, namely, body reality, body ideal, and body presentation [7]. Body

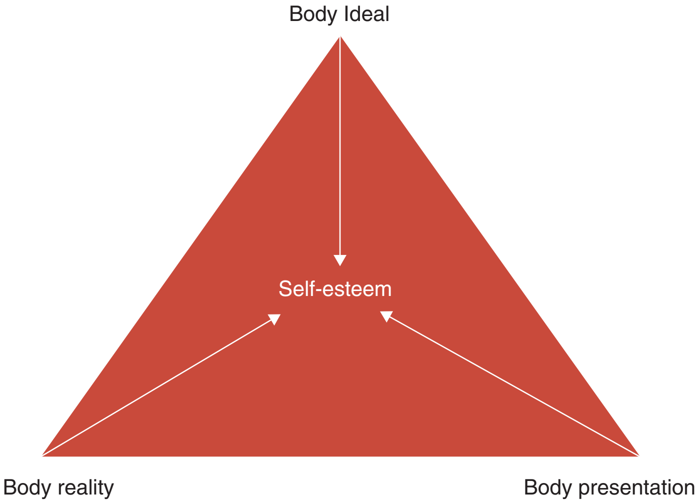

Fig. 5 Price's Body Image Model. Source: Permission from Moorfields Eye Hospital Medical Illustration Department 2022

reality is perceived as the way the body exists after it has been affected by illness, injury, or treatment. Body ideal refers to ideas about how the body should look, feel, or function, and body presentation refers to the ways in which an individual patient can adjust or enhance their appearance. These elements are also embedded within an overarching relationship between mental health, body image, and self-esteem. For the healthcare professional, it is this relationship that provides the basis for assessing and planning the approach to psychosocial care to restore the patient's equilibrium and confidence to return to daily activities. Central to achieving this is the concept of self-esteem, and the healthcare professional has a key role to play in facilitating its re-emergence.

Some of the main aims to be achieved with reference to self-esteem, body image, and mental health are as follows: (1) self-esteem—reaching the stage whereby patients are able to state that they are now feeling confident and capable of accepting and managing their altered body image, they can respect themselves, and they can place realistic expectations both on themselves and others; (2) body image—reaching the stage where patients can say that they are comfortable with the way they look and that they are in tune with what their body needs and it is important for patients to confirm that their appearance has nothing to do with their own sense of worth, value, or abilities, and as people, they remain the same; (3) mental health—reaching the stage when patients can say that they are making time to take care of themselves, even when they are facing difficult feelings or situations. It is important when patients can say that they are working on solving problems and that they are beginning to handle disappointments and difficult feelings. Finally, perfection in handling such situations every time is not always achieved and that is acceptable. It does not detract from the patient's worth.

Some psychosocial points of care will now be discussed with reference to these concepts and altered body image with reference to the illustrated ocular conditions.

5.2 Losing an Eye

The eyes form an integral part of an individual's identity, and the loss of an eye can cause considerable anguish as well as affect an individual's confidence, mental health, and quality of life [24]. Facial disfigurement as a result of losing an eye can be the consequence of trauma and nonmalignant or malignant ocular disease followed by surgical treatment such as enucleation, evisceration, or exenteration (see Fig. 1a). The emotional experience of losing an eye through such surgical interventions followed by appropriate prosthetic restoration is extremely distressing for the patient, family, and friends. This distress is essentially driven by appearance concerns and anxiety about losing sight, all of which will become part of that individual's newly imposed body reality [7]. Saxby et al.'s study found that about 40% of patients indicated a loss of confidence as a result of surgery, and, significantly, a lack of emotional support was cited in 44% of patients. Thus, to maximize postoperative quality of life, a holistic approach, involving counseling and psychotherapy, is essential [24].

5.2.1 Psychosocial Care

Initially, the patient will be entering into a process of grieving for the loss of appearance and consequently will be facing the daunting psychosocial challenges of accommodating an unwanted appearance into a new self-identity [18]. At the same time, shaming, stigmatizing stares, and comments from strangers in daily life may be experienced. This is where the healthcare professional's skills of helping and supporting the patient and family through the grieving process will be critically important. This will involve dealing with the individual's shock, anger, distress, loss of control, loss of self-esteem, depression, and inability to rationalize the situation. Individuals often feel isolated in their experience of disfigurement following surgery such as exenteration of orbit and feel disconnected from themselves, family, and close friends. The feeling of disconnection from close interpersonal relationships can also be made worse by the sick and disabled role being imposed on them by their loved ones after such extensive surgical intervention. For many individuals, the most challenging aspects are related to employment as the loss of an eye and visual impairment may prevent a return to their careers and the self-esteem that was integral to it [18].

5.2.2 Counseling

The healthcare professional must provide opportunities to talk with the patient, and active listening is an important part of the healthcare professional's role. Evidence indicates that one-to-one counseling sessions are a desirable form of support both pre- and postoperatively [24]. Creating a conducive environment to make the patient feel comfortable and relaxed can help promote more effective communication. A trusting and therapeutic relationship with the patient is essential as the sense of loss is intense. Maintaining confidentiality and respecting the patient's privacy and dignity are essential because of the stigma and discrimination associated with facial disfigurement. Patience and understanding will be required when the patient feels the need to express anger, fears, and other negative feelings about their facial disfigurement and sight loss. Evidence suggests that anophthalmic patients exhibit increased levels of emotional stress, depression, anxiety, and even hostility compared with control subjects [25]. However, counseling is emotionally liberating and can gradually bring the patient closer to acceptance of their situation.

It is also important for the healthcare professional to involve family and friends to facilitate recovery and move forward [18]. Patients can use the safety and security of the family unit to develop confidence in talking about their disfigurement and its impact and learning how to use humor to normalize the everyday challenges of monocularity. Patients can learn to talk openly about their disfigurement relating to it in a more humorous way and use their experience of this as a basis for talking to others outside the family [18]. This is a confidence-building experience that will help to restore self-esteem.

Overall, talking therapies can be very effective in facilitating the restoration of self-confidence and self-esteem and a return to positive mental health although the rates of progress for individuals may be variable. For those patients who are finding it difficult to emerge from their clinical anxiety and depression, a referral will be necessary for further professional counseling or cognitive behavioral therapy for a period of time. It is vital that mental health support is routinely embedded within the provision of current services to facilitate the emotional support needed, thereby reducing the stigma associated with referrals to mental health services.

5.3 **Herpes Zoster Ophthalmicus** (Fig. 4)

The healthcare professional's role will be to manage the psychosocial care of adults and older adults with herpes zoster ophthalmicus (HZO) in the community, as most patients will be cared for at home. The key psychosocial aspects of care include effective communication and counseling and the management of pain-related depression.

5.3.1 Psychosocial Care

Good communication and counselling skills are essential. Patients are often distressed and frightened by the nature of this condition and require reassurance and support [26]. It is important to reduce patients' fears and anxieties about potential ocular complications arising, the possibility of sight loss, and poor body image as a result of skin disfigurement. Initially, following the onset of HZO, this becomes the newly imposed body reality. Patients can also become anxious that they are infectious and may transmit the infection to others. It is important to educate patients about HZO and its treatment. Patients will also need to be reassured that they will receive ongoing treatment in the outpatient department, which is important for the monitoring of complications such as dry eyes and corneal lesions, which can compromise eyesight [26].

5.3.2 Counseling to Regain Self-Esteem

The healthcare professional's role in counseling patients to re-establish self-esteem is vitally important. Undoubtedly, loss of self-esteem results from disturbances to body image following facial skin disfigurement and pain-related depression. For skin disfigurement, patients should be encouraged to take an interest in their personal appearance, such as personal hygiene and hair care. A positive interest in patients' feelings and behaviors needs to be demonstrated by listening and talking with them and providing reassurance about their external appearance. Nonverbal communication skills such as skillful and appropriate use of touch and demonstration of affection such as a handshake or a brief, gentle touch on the patient's arm can convey a genuine sense of empathy and caring.

Patients with HZO feel unwell because of severe facial pain associated with the acute phase of the condition [27] or the later complication of persistent, debilitating post-herpetic neuralgia, which may lead to depression [28]. Pain can be exacerbated by the slightest touch, and depression may lead to loss of employment and social isolation. Pain is a strong predictor of the onset and persistence of depression, and because depression lowers the pain threshold, it is a powerful predictor of pain. Concurrent pain and depression have a much greater effect than either disorder alone on the patient's functional status and use of healthcare resources [28].

Alongside the provision of appropriate analgesia depending on the severity of pain, the healthcare professional's effective counseling skills are instrumental in supporting patients and their families to manage some of the consequences of pain-related depression. This means addressing the symptoms of depression, which include altered mood, anger, anxiety, confused thinking, decreased self-esteem, fatigue, irritability, and sleep disturbances [29].

Loss of self-esteem and depression can lead to difficulties in patients adhering to treatment regimens [30]. It is important for healthcare professionals to appreciate the effect of individual belief systems on medication adherence, especially in older people. Patients may not believe in the effectiveness of the medication they are taking and may feel that the side-effects outweigh the benefits. However, if patients can be helped to see that prescribed medication is beneficial, or necessary, they are more likely to adhere to treatment [30]. Clearly, adopting a positive attitude toward patients and stressing the benefits of adherence to treatment will help strengthen patients' beliefs about the importance of maintaining control over their condition.

5.4 **Strabismus** (Fig. 2)

Strabismus (Squint) occurs when the eyes are not aligned and point in different directions. This is the body reality. Squint alters physical appearance, has the potential to disrupt visual development and function, negatively impacts overall health, and results in psychological distress [31]. Squint is a public health concern for many reasons. Importantly, however, the belief that squint cannot be corrected in adults and that children should wait until they are older before receiving treatment are two common misconceptions about adult squint and childhood squint, respectively.

A child will not grow out of a squint, and an uncorrected squint will result in functional blindness in the squinting eye. Treatment of a child's eye before the age of five will maximize the chance of establishing a normal binocular single vision. For adults, treatment of a long-standing squint will not restore useful vision, but it will be of cosmetic value.

5.4.1 Psychosocial Care

The psychosocial impact of squint lowers a person's quality of life and self-esteem and increases levels of anxiety, depression, social avoidance, and social anxiety [32].

Negative attitudes persist toward people who are affected, resulting in difficulties with self-image and consequently lowered self-esteem and confidence. Children with squint are at increased risk of irreversible vision loss, ultimately limiting their future opportunities, and this means that parents face many challenges. Adults with squint experience higher levels of anxiety which may have a negative effect on their self-image and lead to some adults using adaptive techniques to hide their squint [33].

Integrating patient education programs incorporating information regarding the eye condition, treatment options, and advice as to how to self-manage their situations and treatment outcomes can have long-term benefits in delivering a more patient-centered care. This helps to understand the patient's perspectives and better support them to self-manage and reformulate their thoughts and adaptive strategies. Additionally, facilitating well-coordinated social support from family and friends is crucial to improve patient outcomes [33].

5.4.2 Counseling

Counseling the parents of children affected by squint is a very important part of the healthcare professional's role in providing psychosocial care. As with the other ophthalmic conditions already discussed, the role of the healthcare professional is to help and support the individual to regain sufficient self-esteem and confidence to progress toward an acceptable body presentation as a basis for achieving quality of life. Thus, a child's self-esteem can be increased by facilitating both child and parent toward achieving a new body presentation via appropriate treatment and surgical intervention in the early stages.

Misinformation about treatment options for children and adults with squint continues to exist and results in decreased access to care. Improving the education of healthcare providers therefore can help increase appropriate referrals and initiation of treatment. Significantly, the treatment of a squint has the potential to improve psychosocial health and quality of life for children and adults. By introducing a multidisciplinary and multiagency approach, an effective and well-coordinated patient-centered care can be achieved.

5.5 Thyroid Eye Disease (Graves' Ophthalmopathy) (Fig. 3)

In Graves' disease, the body's immune system attacks the tissue of the eyes, causing swelling and bulging (exophthalmos). This results in pushing the eyes forward, making the person look like they are staring. The eyes can also become very bloodshot and strained, and when the inflammation is severe, vision can become compromised due to damage at the front and back of the eye. This is the body reality for someone with thyroid eye disease (TED). This can cause mental health and cognitive problems, anxiety, and depression and can contribute to feelings of low self-esteem or mood [34]. This condition can lead to disability and aesthetic changes to the face such as problems with the alignment of the eyes (strabismus) and double vision alongside ocular pain, impacting the quality of life and resulting in mental health challenges for some patients. Such changes and symptoms culminate in an individual experiencing a decreased sense of well-being and difficulties functioning in social situations as a result of loss of self-esteem, confidence, and social isolation. In addition, having to leave a job, give up hobbies, and limit social situations may give rise to increased feelings of stress leading to anxiety and the gradual onset of depression [35].

5.5.1 Psychological Care and Counseling

Thyroid eye disease (TED) can be a life-changing experience. A multidisciplinary approach is required to help and support patients with TED to maintain mental health and regain self-esteem. Encouraging patients to join support groups, developing a sense of community, and sharing similar experiences with others can help patients to develop insight and resilience to address the social isolation which TED often creates. Importantly, the healthcare professional can provide some basic guidance about self-help, which includes (1) practicing self-compassion, self-love, and patience when situations become difficult; (2) maintaining or creating a sense of community through support groups or hobby groups—in person or online—to help boost spirit and resilience; and (3) regular exercise as regular movement helps to boost both mood and hormone levels [36]. For community support, The Graves' Disease and Thyroid Foundation offers support groups that can help patients to learn more about TED, share experiences, and find support.

Furthermore, developing an acceptable body presentation can be achieved by treatment and appropriate surgical intervention. This process needs to be managed by healthcare professionals working within a multidisciplinary team comprising an endocrinologist, ophthalmologist, or optometrist for medical treatment and an oculoplastic surgeon or neuro-ophthalmologist for surgical treatment [35, 34].

Initially, however, the patient will be advised to seek psychosocial help and support from a GP and care team. Following the assessment of the patient's condition and psychosocial needs, appropriate referrals can be made with reference to mental health impact. Referral can be made for NHS psychological therapy services—also known as Improving Access to Psychological Therapies (IAPT) services—such as counseling and cognitive behavioral therapy for depression [36].

6 Positive Mental Health

With reference to all the ophthalmic conditions discussed, regaining self-belief and self-esteem sufficiently to be able gradually to accept a newly restored body presentation will subsequently form the basis for achieving a positive state of mental health and quality of life. Thus, the healthcare professional's psychosocial caring role within a multidisciplinary and multiagency approach in facilitating a return to psychological well-being and quality of life for all patients with facial disfigurement due to ocular disease is vitally important and significant.

Overall, Price's Body Image Model is a helpful tool for providing the psychosocial care of patients with altered BI due to ocular disease. Table 1 below summarizes how the model can be utilized with effect by all healthcare professionals to help patients regain confidence and self-esteem.

Table 1 Summary, Key roles of the healthcare professional, and outcomes of Price's Body Image Model in Healthcare

Price's BI Care Model elements	Key roles of healthcare professional	Outcome
Body ideal is how an individual would like to appear and behave with others **Body reality** is the objective form or phenotype of the body, the result of genetic and environmental influences **Body presentation** is how an individual presents the body externally, through dress, alteration, and behavior **Self-esteem** refers to a state when an individual feels confident and is capable of accepting and managing their altered body image that they can respect themselves and place realistic expectations both on themselves and others	• Coordinate and support family members and friends to help patients in developing self-acceptance, coping with their situation • Create an appropriate environment for regular therapeutic conversation, demonstrating privacy, respect, and dignity • Listen actively to the patients • Respond positively with sensitivity to help patients to make decisions regarding their body presentation, thus restoring their self-esteem • Ensure therapeutic engagement with the patient	• Acceptance of self • Managing feelings competently • Coming to terms with situations • Restoration of self-esteem • Positive self-image • Positive social interaction • Quality of life

7 Conclusion

Many ophthalmic eye conditions do alter the patient's BI. Patients with a wide variety of ophthalmic conditions are concerned about the appearance of their eyes, as well as issues relating to functional deficits. The psychological impact of disfiguring eye conditions is well documented, causing patients to experience anxiety, clinical depression, distress, and social avoidance. Body image develops relatively early in life and can affect children, adolescents, and adults. Anyone can be affected by a disfigurement or an unusual appearance at any time. This can be a condition from birth or caused by an accident, or an illness, or an injury due to a violent act or self-harm. Many patients with eye conditions may present with an altered BI; thus, a careful assessment and empathy are essential. Each patient case scenario must be individually evaluated, and care given must be patient centered. The BI model provided by Price is an excellent platform to address the care of ophthalmic patients who present with certain eye conditions. Each patient may present with different challenges; thus, a holistic approach to care is important. Reflecting on patients with ophthalmic-altered BI should be viewed as a learning journey. Altered body image remains an important public health issue; thus, referring the patient to an appropriate agency is essential. Psychological intervention may impact positively, and advice and emotional support must be made available to those who need it.

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Chapter 4: Stigma Related to Sight Loss and Psychosocial Care

Swapna Naskar Williamson

1 Sight Loss and Its Impact in a Social Context

The progressive increase in cases of visual impairment and the future estimated prevalence of vision loss from 7.8 billion in 2020 to 9.7 billion in 2050 poses a challenge for healthcare professionals in meeting the psychosocial needs of people with sight loss. They often experience social isolation, anxiety, and depression due to negative social views of disability, discrimination, pity, and stereotyping, leading to a loss of self-confidence, independence, and social identity [1].

Sight loss affects people of all ages, and its risk increases with a person's age. The challenges and emotions presented by sight loss are as varied as the different types of eye conditions [2]. The impact of sight loss depends on how people perceive and interpret the world, which is used for everyday communication, social

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activities, educational and professional attainment, maintenance of personal health, independence, and mobility. In children, normal sight contributes to their social development, academic achievement, and better health across the life span. Sight loss at any age is frightening and can be traumatic as it has a significant impact on those who experience it, their families, and friends [3]. People with sight loss experience challenges in social participation leading to isolation and affecting their psychosocial well-being despite the availability of compensatory visual strategies and technologies [4]. They may experience continuous mental stress due to worries, anxiety, economic loss, and fear of secondary consequences such as depression and social isolation. They may also be overwhelmed with the diagnostic procedures, treatment modalities, technology advice, training, and associated information, posing communication challenges as they are unable to read, recognize faces, and distinguish facial expressions, leading to further reduced social interactions and engagement. Thus, they become dependent, feel helpless, and experience psychosocial and socioeconomic consequences leading to a decreased quality of life [3, 5, 6].

Sight loss can be either a visible or invisible disability [2, 7]. It refers to the impairments, limitations, and restrictions that a person with an eye condition faces in the course of interacting with their environment in a physical, social, or attitudinal context [6]. Sight loss results in impaired mobility leading to falls, injury, and worsened social status [3, 5]. People with sight loss are labeled as disabled who are no longer seen as an individual but as part of a stereotyped group. They experience exclusion, disapproval, and rejection by others. Stereotyping is a barrier to social participation in older adults with low vision [4]. Lack of social inclusion and meaningful participation in the community result in individuals' loss of identity, dignity, security, and opportunity to lead a better life. They may feel segregated, excluded, and ignored in society, compromising their independence and quality of life. Sighted people and people with sight loss construct stigma through social interactions in which "normal" people discredit individuals with stigmatizing characteristics. Similarly, stigmatized individuals employ strategies to deal with the rejection of others and the complexities of their perceived status, which reinforces the notion of stigma as a fixed identity residing within an individual [8, 9]. Consequently, stigmatized individuals constantly strive to adjust to their precarious social identities.

2 Stigma: Conceptualization and Theory

Stigma originates from a Greek word "stigmata," which refers to a physical mark that was originally cut or burned into the skin of criminals, slaves, or traitors in order to visibly identify them as blemished or morally polluted persons. These individuals were to be avoided or shunned in society. The word evolved into a sociocultural constructed sign of social disgrace that was later applied to other personal attributes that are considered shameful or discrediting. Marks become associated with discrediting dispositions, negative evaluations, and stereotypes, which are generally shared and well known among members of a culture and become a basis for excluding or avoiding members of the stereotyped category [10]. Stigma characterizes specific attitudes and beliefs, leading people to reject, avoid, or fear those they perceive as being different and distinguishing between socially acceptable and unacceptable behavior. Thus, stigma comprises of lack of knowledge, negative attitudes, prejudice, and discriminatory behavior toward the disadvantaged or stigmatized person [11, 12].

People suffering from mental illnesses, cancers, HIV, AIDS, and skin conditions are often undermined by stigmatizing attitudes and discriminatory behavior toward them. Misconceptions due to cultural or religious beliefs and a lack of awareness and understanding about the causes and characteristics of disabilities may often result in stigma. For example, disability is often blamed on misdeeds of ancestors, parents of the person with disabilities, supernatural forces such as demons and spirits, witchcraft, punishment, or fate from God. Misconceptions also exist about the abilities of people with disabilities that they are unable to contribute financially, to have a normal relationship, and to interact with others contributing to discrimination [11, 13].

Goffman, the leading theorist in the field of stigma, defines stigma as “an attribute that is deeply discrediting” [8] and emphasizes two major consequences of stigma: status loss and social rejection. Stigma is an attribute that extensively discredits an individual reducing from a whole and “normal” person to a tainted, discounted one, who is to be avoided. Thus, stigmatization occurs when a person possesses some attribute or characteristic that is devalued in a particular social context, which marks them as being different in the eyes of others [10]. Moral and social disapproval, isolation, exclusion, and avoidance are also evident toward people with sight loss and disfiguring ocular disease. Categorizing or labeling a person with sight loss as “the blind” instead of their personal attributes permits society to feel that stigmatized individuals are fundamentally different and contributes to a greater psychological and social distance [14].

Goffman’s Construction Stigma Theory distinguishes “normals” and stigmatized individuals who possess a discrediting attribute and emphasizes the psychological impacts on stigmatized individuals.

1. Spoiled Social Identity: Within society some attributes are desirable and normal whereas others are undesirable and unacceptable. Consequently, individuals are categorized as acceptable or unacceptable, which becomes the norm of social identity. A discrepancy between society’s expectations and an individual’s actual attributes can result in stigma. The social identity becomes “spoiled” where even positive attributes of the individual are minimized and overruled by the negative assessments others make as they assess the disabling conditions [14]. Thus, the undesirable attributes of an individual that contradict society’s stereotypes become the key identifying characteristic transcending all other aspects of the individual.
2. Social Labeling: Stigma can occur when people identify and behave in ways that reflect how others label them. It is a process of categorizing attributes of an individual that are not considered “normal.” Stigma is a labeling process by which a statement or word is attached to a “different” characteristic or

> attribute of an individual, and the labeled person suffers from status loss [8]. Individuals who become associated with a stigmatized condition pass from a "normal" to a "discredited" or "discreditable" social status. Thus, Goffman viewed stigma as a process based on the social construction of identity.

Goffman's original discourse of stigma included both psychological and social elements, but his ideas have primarily been used to analyze the psychological impact of stigma on individuals. This has created an understanding of the psychology of a stigmatized individual and the process by which stigma is internalized that shapes individual behavior. There has been limited discussion on how social life and relationships are changed by stigma.

Since the 1960s, the concept of stigma has undergone significant change. Stigma is an interactional process that exists within a social and cultural context and is perpetuated by the acceptance of stigma by the stigmatized [15]. Research in the field of sociology identifies a broader concept of stigma as a social process that occurs within the sociocultural context affecting individuals, which involves power relations. Power is the cause of stigmatization. Stigma encompasses a component of structural discrimination or the institutionalized disadvantages placed on stigmatized groups. Thus, stigma refers to the co-occurrence of its components of labeling, stereotyping, and cognitive separation into "us" and "them" groups with status loss, social rejection, and discrimination. For stigmatization to occur, power must be exercised, leading one group to successfully devalue the other [9]. The stigmatized group is compelled to align themselves with those devalued identities designed by the norms of society. Stigmatization is contingent on socioeconomic and political power distribution as only powerful groups can fully disapprove and marginalize others leading to various forms of disapproval, rejection, exclusion, and discrimination that allow the identification of "differentness" and the construction of stereotypes [9, 16]. The impact of social exclusion and how social life and relationships are changed due to stigma is an important phenomenon [17]. Stigma often has moralistic overtones, with individuals seen largely at fault for any illness that befalls them. The illness or attribute, such as sight loss, is essentially a part of an individual, and it is not acquired by choice.

3 Stigmatization of People with Sight Loss

Stigma, a social phenomenon, is commonly influenced by both historical and cultural forces [18, 19]. As in ancient Greek societies, stereotypes and prejudicial attitudes are still attributed to people with sight loss, contributing to a public health issue that poses a global financial burden [3, 4, 20]. People with sight loss are often victims of superstitions, indifference, and pity from the sighted society. Consequently, they suffer from stress, anxiety, and depression, which they are hesitant to discuss with healthcare professionals [21, 22]. Furthermore, people with visible facial disfigurements following eye surgery i.e., exenteration, enucleation, or evisceration, with altered body image may encounter identity issues. Thus, they experience difficulties in coping with lost eyes and the use of prosthesis resulting in extensive psychosocial problems, stereotypes, and discrimination.

Stigma, prejudice, and discrimination of people with mental illness are well documented. People with sight loss experience social stigma as well as their mental health problems. Social stigma may exacerbate depressive symptoms and the development of self-stigma. Self-stigmatization is the result of internalizing negative stereotypes, which prevents the person from seeking help and receiving treatment [22]. Thus, they have not only personal vision loss but also negative self-perceptions as a result of social stigma. Goffman explains sight loss is a stigmatizing condition that makes someone “not quite human” [23]. Consequently, individuals become victims of negative social relationships and interaction, which becomes a barrier to social inclusion resulting in social isolation affecting their quality of life [4, 14, 24]. The process of being labelled by other people hinders their adjustment to visual impairment.

Despite initiatives at local, national, and international levels to support people with visual disabilities, they are helpless, dependent, and unemployed or are nearly five times more likely than the general population to have had no paid work [25, 26]. Some individuals are employed in professional, administrative, and secretarial sectors, but the question frequently being raised is, "What jobs do blind and partially sighted people do?" [27]. In some developing countries, people with sight loss have small-scale jobs such as making and selling candles and pencils or working in small-scale industries. In modern society, some people with sight loss are independent, have self-supporting lives, and are fully integrated into mainstream society. Furthermore, the fear of stigma and discrimination can cause people with sight loss being reluctant to seek support and being labeled by others as a fraud [28].

Psychological problems experienced by people with sight loss have been recognised; however, there is a dearth of literature regarding stigma relating to sight loss. The use of supportive devices may have negative effects on the well-being of people with sight loss leading to lower self-esteem, confidence, depression, anxiety, and unfavorable reactions, i.e., staring, unwanted support, and questions. This can cause further stress, anxiety, embarrassment, negative social interaction, and relationships. There is limited empirical research published on stigma related to visual disability. Some excerpts from the available research findings and case studies demonstrating lived experiences have been used to portray how people with visual impairment and sight loss feel being labeled and stereotyped and encounter a range of barriers in social interaction and accessing employment opportunities [4, 22, 29].

Due to limited access to information, transport, education, training opportunities, and attitudes of employers, people with sight experience employment difficulties. Study findings suggest that disclosure of visual impairment in the workplace can result in constructive dismissal, denial, and lack of promotion opportunities, demotion, and negative attitudes from the employer [24, 26]. Furthermore, some people with sight loss find it challenging to progress to the interview stage even though they are successful in telephone interviews [24]. In healthcare settings, people with sight loss should feel safe and be understood, but quite often their needs are overlooked. For example, the receptionist in a general practice surgery forgets to advise the person with sight loss when their doctor is ready to see them. They find that healthcare professionals often fail to communicate information of a sensitive nature effectively. They face barriers in obtaining health-related information because it is inaccessible, i.e., posters in a waiting room or information on a website [22, 24]. Ignorance and stigmatizing attitudes toward people with sight loss potentially result in social exclusion and interrupt the natural flow of communication [4]. One participant in the study states:

> When you're visually impaired it's like, you drink out of my cup, you are going to get it. It's contagious, if I touch you, I sneeze on you, that's it, tomorrow you are going to be blind. That's the conception out there.

People with sight loss often feel excluded from social events. They experience negative attitudes from the public, especially when using a white cane, and feel shame and embarrassment affecting their sense of well-being despite its importance as a mobility device [25, 30] Thus, these assistive devices may become a double-edged sword as the mindset of the user and the people they interact determine either positive or negative conceptualization of the use of these devices. Parents need to educate their children early on about the use of the white cane, which will enable them to develop sensitive and empathetic attitudes toward people with sight loss. Lived experience of a volunteer's includes [31]:

> ... it devastates me when parents shush a child when all they've done is try to learn more about the world. Shushing your child tells them that my white cane, my disability and therefore my existence is taboo. It teaches them that disability is shameful, it mustn't be acknowledged or spoken about. It makes disability frightening.

Open and honest curiosity of children is an essential prerequisite for gaining new knowledge and experience. Answering their questions about the use of white canes should be factual and must not be seen as a rude or embarrassing. Factual and clear explanations to children will help them to learn about disabilities in a positive way and make them to be compassionate and develop a realistic view of the world.

4 Effects of Stigma on People with Sight Loss

People with sight loss experience a loss of independence and limitations on active control of their will and surroundings, thus affecting their wellbeing and quality of life. Additionally, undesired discriminatory attitudes from society pose a great risk to their mental health deviating them from social norm resulting in their stigmatization and exclusion from society.

4.1 Social Isolation and Loneliness

Social isolation, restricted mobility, feeling of loneliness, and a decrease in social status affect the quality of life of people with sight loss [25, 32]. They have limited opportunities to acquire social skills, which may affect their social interaction and ability to build relationships, resulting in loneliness. Consequently, the loss of social activity leads to experiences of insecurity, stress, anxiety, and depression. They also encounter a lack of social support and a reduction in general well-being leading to social isolation [33, 34]. Furthermore, individuals using assistive devices and measures including white cane, guide dogs, braille, specialist phones, and computers may feel stereotyped, which leads to a loss of identity and developing stereotypical attitudes toward themselves resulting in self-stigma [35, 36].

4.2 Stress and Negative Attitudes of Others

People with sight loss experience stress, anxiety, and fear of vulnerability and social isolation [5].

Due to a lack of access to relevant information, accessibility to work, appropriate workspace, financial instability, limited inclusive activities, and social stigma people with sight loss may feel discriminated and marginalized. However, the nature and extent of marginalization and discrimination are dependent on the exposure of society to the stigmatizing trait or disability. Therefore, the attitudes will vary when a person with sight loss is interacting with friends and family, as opposed to a group of strangers [4]. The attitudes of family members toward the person with sight loss have a direct relationship with how the person accepts his or her disability. Acceptance from family and the wider society is crucial to self-acceptance when considering visual disability. Thus, familiarity with the stigmatizing trait or disability is an important factor in determining whether an individual is stigmatized.

4.3 Education, Employment, and Travel Challenges

People with sight loss experience challenges in the areas of education, employment, travel, and transport as they are different than the normally sighted people. Their financial problems are worsened due to a lack of education and employment opportunities [37].

4.3.1 Education

Individuals with sight loss or visual impairment experience educational challenges as the educational programs are designed and oriented toward sighted people. Labeling and negative attitudes by others can obstruct people with sight loss access to schooling and educational opportunities. They also experience problems in listening, reading, writing, understanding the concepts, and even communicating with others, which can lead to frustration, stress, loss of hope, and aspirations. This may result in their developing negative attitudes and lack of interest toward educational institutions, subjects, learning materials, and teaching/learning strategies. Consequently, they may even discontinue their education and drop out of school [38]. This results in social isolation, negative attitudes, and labeling. This can be addressed by designing an inclusive curriculum ensuring the effective use of appropriate technology, assistive devices, and equipment.

4.3.2 Employment

Sight loss may lead to barriers to employment. People with sight loss may require specialist support to be employed as compared to the general population or people with other disabilities [25]. However, some people with sight loss work successfully in some areas, but they are often seen as being capable of doing a narrow range of jobs [39] and nine out of 10 employers rate people with sight loss and visual impairment as either “difficult” or “impossible” to employ [36]. Once in employment, they encounter challenges and eventually are compelled to leave their job due to the onset or deterioration of their sight loss or due to inadequate support and resources to continue in their job [25, 39].

4.3.3 Travel and Transport

Limited mobility is a common challenge faced by people with sight loss [25, 40]. The problems related to accessibility include navigating around obstacles on pavements such as parked cars, bins, poorly maintained pathways, and overhanging hedges. They find it challenging crossing roads, using public transport, and obtaining travel information, which make people with sight loss particularly vulnerable and at risk of accidents. Their inability to travel independently causes constant frustration, stress, and resentment [40]. Therefore, appropriate policies and standards related to transport services need to be introduced to incorporate the key support strategies to provide a more inclusive service. Training of transport operators and staff, strategically placed pedestrian crossings, and more availability of real-time information would bring the greatest mobility benefits to this disadvantaged group.

4.4 Psychological Challenges

People with sight loss encounter a range of psychosocial issues (See chapter “Living with Ocular Disease and Quality of Life” for details). They become more vulnerable and are reluctant to discuss their mental health problems with family, friends, and healthcare professionals due to stigma associated with mental illness [41, 42]. They tend to deny psychological distress due to social stigma attached to depression or perceived negative consequences of acknowledging depression and anxiety.

Stigma imposed by the social environment may also result in self-stigma, which occurs when an individual develops negative attitudes about themselves due to stereotypical behavior posed toward them by society [15]. Self-stigma usually develops in three stages: first the stigmatized person realizes that they have been stereotyped, and then they accept the stereotype and finally apply it to themselves. Social stigma hinders the rehabilitation process of people with sight loss and increases the recurrence of self-stigma. Psycho-education can potentially reduce self-stigma; therefore, healthcare professionals should be equipped with culturally competent specialized knowledge and skills to address mental health problems of people with sight loss experiencing stigmatization [43]. Stigmatization also has a negative impact on self-esteem, self-perception, and mood resulting in depression and lack of confidence affecting an individual's social identity as it devalues personal attributes, which is contrary to a norm of a social unit. Stigma also discredits a person in the eyes of others affecting one's self-esteem, values, and self-respect [44].

Furthermore, visible eye disfigurements can result in the development of negative body image (see chapter "The Psychosocial Impact of Ocular Disease on Body Image" for details). This situation is further accelerated through negative attitudes of public and exacerbated by unwanted questioning and staring, leading to labeling and stereotype. Consequently, patients experience embarrassment, anxiety, depression, distress, and dissatisfaction due to negative body image leading to the development of stigma [45, 46]. An improvement in self-image must be facilitated by positive experiences, acceptance, and being valued and respected by other people.

5 Improving Awareness and Education in Reducing Stigma Related to Sight Loss

Identification and implementation of appropriate strategies are the key to reducing the stigma of sight loss. Healthcare professionals and people with sight loss should be cognizant of the causes, prevalence, preventive and therapeutic measures, and rehabilitation processes of sight loss. Equal opportunity, accessibility to resources, to aid disability and avoidance of discrimination must be embedded in care strategies.

5.1 Knowledge about Vision Loss

The eye conditions leading to sight loss are progressively increasing globally and at least 2.2 billion people have a near or distance vision impairment, which could have been prevented or has yet to be diagnosed [20]. Table 1 shows the eye conditions, which may cause visual impairment, sight loss, and its preventive measures.

The data in Table 2 reflect the wider global eye health issues giving rise to the risk of sight loss, specifically within the United Kingdom (UK). In the UK, approximately six million people are estimated to be living with sight-threatening eye conditions [29]. The groups at high risk of sight loss are shown in Table 2.

Table 1 Causes, prevalence, and prevention of visual impairment or blindness

Eye conditions	Prevalence	Preventive measures
Uncorrected refractive error	8.8 million	Wearing the right prescription glasses
Cataract	94 million	Regular check-up as all forms is treatable
Glaucoma	64 million	Early detection and treatment
Corneal opacity	4.Two million	Early detection and treatment
Age-related macular degeneration (AMD)	10.4 million	Early detection and treatment
Diabetic retinopathy	3.9 million	Early detection and treatment
Trachoma	2 million	Early detection and treatment
Unaddressed presbyopia	826 million	Early detection and treatment

Table 2 Groups at high risk of sight loss

Indicator	Result
Older people—Number of people in the UK aged over 60	14.2 million
Later life—Number of people in the UK aged over 85	1.4 million
Low income—Number of people in the UK who are living in low-income households after housing costs	13.0 million
Diabetes—Number of people in the UK who are diagnosed as having diabetes	3.5 million
Smokers—Proportion of adults in the UK who smoke	10.0 million
Learning disabilities—Number of adults with a learning disability	More than one million >1.0 million
Dementia—Number of people in the UK who have some form of dementia	850.000

5.2 Education and Training

Education and training of healthcare professionals and people with sight loss are essential for a better understanding of symptoms of the psychosocial impact of sight loss to eliminate its misconceptions and reduce stigma. Advanced training for qualified nurses can enable them to address the psychosocial aspects of rehabilitation rather than only focusing on the traditional physical rehabilitation of people with sight loss [22]. Healthcare professionals should understand what it means to live with sight loss and adopt appropriate etiquette toward them. Implementation of standard procedures and realistic workloading of healthcare professionals will enable them to detect depression and anxiety in people with visual impairment and sight loss in providing culturally competent person-centered evidence-based care improving their quality of life [11, 47]. Thus, collective education of healthcare professionals and people with sight loss including their family members can lead to improving adaptation to vision impairment and greater life satisfaction. A multidisciplinary education intervention and person-centered care approach can result in inclusivity, support, respect, and dignity that help in eliminating visual disability-related stigma. Additionally, contact-based education interventions will have mixed efficacy having a significant impact in reducing stigma that focuses on more social interaction allowing greater equality status than relationships between healthcare professionals and people with sight loss, thus, reducing social distance [13, 48].

6 The Role of Healthcare Professionals in Supporting People with Sight Loss Experiencing Stigma

Healthcare professionals should be prepared to support people with sight loss enabling them to adjust to living in the "sighted world" (see Chapter "Conclusion" for details). It is challenging for sighted people to fully perceive and understand the needs and problems encountered by this group.

6.1 Identification of Risk Groups and Meeting Their Needs

People with visual impairment and sight loss are at risk of stigma. Their mobility issues, social isolation, limited access to resources, and mental health problems lead to self-pity and withdrawal from society. Their awareness of being stereotyped by the society compels them to accept, acknowledge, and believe that this is their real image leading to self-stigma. It is crucial for outreach workers to educate and encourage people with sight loss to discuss and share their experience relating to their disability with the health and social care staff and their peers. This interaction can help develop insight; thus, nuances within supportive interactions can help people with sight loss cope with stigma [14, 49]. A holistic person-centered care approach can reduce social and self-stigma to improve patients' quality of life.

6.2 Facilitating Social Adjustment and Inclusion

People with visual impairment experience difficulties with activities in living. Restricted mobility contributes to a reduction in social interaction, negatively affecting the psychological well-being of people with sight loss. They are at greater risk of developing low self-esteem and limited social engagement leading to loneliness and social isolation [50].

Healthcare professionals need to collaborate to create an inclusive, safe, and supportive physical and social environment, ensuring that the person with sight loss has facilities put in place in their home to carry out their daily activities, including self-management [24]. A safe and comfortable social environment can help professionals, family members, and people with sight loss to take part in activities as equals. This helps in building positive relationships and developing self-confidence and self-efficacy to live a normal life.

6.3 Humor

A large part of social adjustment, inclusion, and preventing stigmatization requires social skills and learning how to interact with other people in a positive manner. Humor, as a coping strategy, can be used to reduce stress related to sight loss [51]. Having a sense of humor is essential to help and encourage people with sight loss to learn and accept a new way of adjusting and enjoying life, which is the best defense for the prevention of isolation and becoming a target for stigmatizing behavior. Humor can be useful, especially when an individual is emotionally and psychologically affected due to sight loss. Effective use of humor can go a long way in easing the unpleasantness that people with sight loss may encounter due to their circumstances. Being able to laugh is healthy for everyone; when used correctly, humor can even defuse tense and stressful situations. The significance of humor has been expressed by a study participant, “A well-developed sense of humor is the pole that adds balance to your steps as you walk the tight rope of life.” [24].

6.4 Ensuring Personal Safety and Security

Safety concerns relate to both internal and external factors. The most immediate safety concerns relate to the individual's reaction to risks in the external environment such as physical safety in or out of their homes. People with sight loss face challenges in their lives especially due to their vulnerability and need to constantly ensure their own safety. Despite the considerable potential of modern technology, the most effective aids for sight loss are still the white cane and the guide dog. The assumption that cane use implies the person is blind may make it difficult for people with sight loss to accept the use of the cane, which can lead to them using it in concealment. Therefore, they will be unable to benefit from one of their aids to safety, thereby being at a higher risk of danger. There may be a conflict between the use of a cane for safety and the associated social stigma resulting in feelings of shame and embarrassment, which should be addressed with sensitivity to ensure the safety of the individual [52].

6.5 Encouraging Self-Care, Self-Management, and Empowerment

Development of sense of identity, self-worth, and emotional adjustment to blindness are crucial for independence and lifelong success in people with sight loss [53]. Support groups and networking can create opportunities for them to meet people with similar disabilities, thus enabling them to share their experiences and develop insights into better management of their own problems. Appropriate support systems such as peer-group interaction, family, qualified trainers, and community support group should help in developing a sense of self-efficacy, confidence in their own ability, and decision-making skills to achieve their goals [52]. This will enable them to deal with various forms of social discrimination and barriers, ensuring their independence and a better quality of life. Peer support groups can act as an important source of practical information, facilitating self-acceptance, self-confidence, and emotional stability for people with sight loss to become independent in their life journey [15].

6.6 Guiding, Counseling, and Peer Support

Adjustment to sight loss is a complex, challenging, and an active process. Healthcare professionals have a challenging task as they need to be responsive to the needs of people with sight loss experiencing stigma. Recognizing the reluctance of using white cane, feelings of being stigmatized, and shame is the primary step to plan a structured guidance and counseling service for people with sight loss. Treatment options and organizational support based on an individual's need can better help with psychosocial coping mechanisms and enable them to lead a better quality of life [2, 41]. Peer group interaction and active listening to their problems can help people with sight loss to reflect on, be resilient, and develop insight, thus identifying alternative measures to better adjust and make appropriate decisions to lead independent, successful, and quality of life.

6.7 Maintaining Competence in Healthcare Professionals

Being blind is a constant challenge requiring support and guidance. Helping people with sight loss experiencing stigma is a challenging task, especially supporting them to come to terms with the process of re-conceptualization and self-acceptance. Specialized training and education of healthcare staff are paramount to providing culturally competent and supportive care with positive patient outcomes [38]. In-depth knowledge and understanding of the concept of stigma and how people with sight loss experience social and self-stigma enable healthcare professionals to address individuals' psychosocial needs so as to develop self-confidence, thus empowering them locating appropriate care and support from relevant organizations identifying opportunities to lead a normal life. Healthcare professionals need to meet the psychosocial needs of people with sight loss to support them in leading independent, productive, and successful life, thus improving their quality of life. Ongoing training of healthcare professionals is crucial to update their knowledge and skills in providing evidence-based person-centered care to

Table 3 Case study: a lived experience of a person with sight loss

John became blind when he was a teenager. He encountered many challenges, but his strong willpower, self-determination, self-respect, and positive attitudes toward self enabled him to lead a normal life as that of sighted people. He achieved what he aimed for in life, and his achievements were appreciated and accepted nationally and internationally. He is now considered a role model in his community and beyond. An excerpt of his memoir is provided below:

"I was a teenager when I lost my sight. I hated my blindness as I lost my independence and was conflicted with many questions in my mind regarding my future and how to develop myself. It was a big challenge for me as a blind person and to build respect for myself.

As I did not want to follow what the institutions, teachers and parents expected me to do I started travelling to different countries i.e., Morocco, Columbia and India. Although I encountered some difficulties relating to my blindness while travelling, I had an opportunity to discover the world. I met people of different cultures and I kept busy to survive. I started to write, make movies with friends, attended meetings and conferences. Nowadays I am invited in theatre to read my poetry in immersing the audience in the darkness to allow them to experience what being sightless means.

'What is it like to be blind?'

I believe that being in denial of blindness makes it difficult to be in peace. It took 6 months for me to perceive that I was blind as I continued to study in the same school and interacting with the same people. Then I had to move. Only when I moved to another place did I recognise that I was blind. At this point of time, I recognised, the hard work started towards accepting being blind, developing insight to accept my own image.

I can only speak from my own experience, discounting any psychological principles or any formal sources, that in order to fulfil their desires blind people need to take some risks. Teachers, educational institutions and parents are there to give the knowledge of course but they should also allow their students to discover or rediscover their own deep desire. Generally, many people, blind or sighted, live a borrowed life i.e., heavily dependent on others while already having regrets and frustrations. Understanding the inner self and self-acceptance means that blindness does not necessarily define an individual but it is a state of uniqueness as that of any other sighted people. This should rather create inclusivity and not social exclusion.

We are all different, I do not believe in disabled or handicapped persons, you become handicapped when you deny and refuse your individuality."

enable people with sight loss to lead an active, social, and satisfying life. Table 3 depicts a brief-lived experience of a person with sight loss.

7 Conclusion

Sight loss and visual impairment are global phenomena affecting all societies, individuals, and their families who experience significant economic consequences, stereotypes, prejudice, and stigma contributing to discrimination and exclusion in all aspects of their lives. A culturally sensitive, integrated, and collaborative care approach will guide and support individuals with sight loss to cope with their psychosocial challenges. Providing holistic integrated healthcare service based on current evidence develops insight, resilience, and self-confidence to reduce stigma, self-manage, and lead a normal heathy life. Education and training, using contact-based approaches to learning, is crucial that will remain instrumental in allowing healthcare professionals to contribute effectively to achieving a high standard of evidence-based psychosocial care within a holistic framework as part of an integrated healthcare service.

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Chapter 5: Living with Ocular Disease and Quality of Life

Susan Watkinson

1 Emotional Reactions

The key emotional reactions of sight loss due to ocular disease often manifest as stress, anxiety, low self-esteem, feelings of loneliness, depression, and sometimes as suicidal thoughts and even suicide. Sight loss has been compared with the feelings experienced following a significant loss in life and the stages of grief subsequently encountered, which include shock, denial, anger, fear, anxiety, and depression [1]. Shock, for example, is most often experienced following the diagnosis of ocular disease and can be traumatic, particularly where the existing ocular condition has deteriorated or an additional condition has developed. The sudden development of an ocular condition for which no further treatment can be offered and the current treatment can only help maintain existing vision, for example, in age-related macular

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degeneration (AMD) and primary open-angle glaucoma (POAG), is particularly distressing. The diagnosis may also indicate the ocular condition could get worse [1]. Coming to terms with the diagnosis of ocular disease and sight loss is a challenging emotional situation for the individual.

2 Quality of Life

Quality of life (QOL) has been defined as “individuals’ perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” [2]. This definition is salient when applied to ocular disease. Sight loss impacts the attributes of QOL including physical, social, and emotional well-being.

The emotional impact of sight loss in reducing a person’s quality of life is well documented in clinical literature. Vision loss in later life contributes to limitations on physical activity, reduces independent mobility, causes falls and imbalance, and increases the risk of hip fracture and mortality, thus underlining the need for community and family support. Population aging therefore has become an important social issue worldwide, and improving the quality of life is one of the biggest challenges for healthcare professionals [3, 4]. Visual impairment has a negative effect on health-related quality of life (HRQoL), particularly among nursing home residents where HRQoL becomes reduced and bears a positive association with visual impairment [5]. The concept of well-being is also strongly associated with older people and their quality of life [6]. Clinical evidence suggests older people with visual impairment are more likely to score negatively on measures of well-being than sighted people. In examining three outcomes related to the concept of well-being, namely, quality of life, psychological health, and depression, it was found that older people with poor vision were between three and five times more likely to score negatively on those measures than those with good vision. Overall, older people with visual impairment are much more likely to report indicators of low quality of life, poor psychological well-being, and depression [6]. Furthermore, social networks and social participation are also strongly associated with quality of life. The quality of social relationships, such as spousal relationships, relationships with children, and not having negative social relationships, is poorer for those with sight loss compared with those with good or better vision. Those with sight loss are significantly less likely to use written forms of communication with members of their social networks, such as emails or letters. Those people with some sight loss are less involved in social, civic, and cultural activities such as organizational membership, volunteering, or having a hobby, than those with good vision [6].

Equally, psychological well-being can become impaired in younger age groups with vision loss [7]. In examining the consequences of profound vision loss on important aspects of psychological well-being in adolescents, young adults, and middle-aged adults, significant psychological morbidity was experienced. Approximately, half the research participants became clinically depressed and many reported profound negative effects on their interpersonal interactions and career-related goals [7]. However, factors improving the quality of life and emotional health included the role of ophthalmologists in the emotional adaptation of visually impaired patients with reference to the efficacy of using electronic low-vision aids [7].

3 Ocular Disease and Quality of Life

Ocular diseases such as cataract, POAG, and AMD can often affect the quality of life.

A cataract is an opacity of the lens that develops slowly over several years with gradual blurring of vision not improved by wearing glasses. In the advanced stages of cataract development, patients may perceive only hand movements [8].

Sight loss due to cataract can have a major negative effect on the quality of older people's lives with practical implications [9]. Activities of daily living, such as washing, dressing, cooking, reading, watching television, and even walking, can become harder to undertake as a result of sight loss. More significantly, people who cannot detect ground-level hazards, such as steps, kerbs, and pavement cracks, are more likely to fall and sustain injuries, such as a hip fracture, which can subsequently increase the likelihood of their eventually being admitted to nursing homes [10]. Reduced participation in social activities can lead to a sense of isolation and loneliness and the possible gradual onset of depression [11]. Experiencing diminished sight can be unsettling, stressful, and anxiety-provoking, leading to loss of confidence, independence, and freedom [12]. Research suggests that activity restriction may negatively affect psychological health and social functioning and supports interventions that focus on maintaining and enhancing physical and social functioning [13]. Surgical intervention has been proven as an important means of improving vision for older people to restore physical and social functioning in return for an enhanced sighted quality of life. Psychosocial support during the assessment and pre- and postoperative stages of cataract surgery is critical to successful rehabilitation back to a sighted quality of life.

3.1 Cataract

3.1.1 Psychosocial Theory and Care

As a health educator, the healthcare professional's application of psychosocial theory to practice is invaluable in providing effective ophthalmic care. It is particularly beneficial when older people have to make informed decisions about the need for cataract surgery [10]. Some older people harbor the misconception that vision loss should be accepted as part of growing old and are reluctant to seek medical advice and treatment [13]. The provision of accurate and relevant information to older patients requiring cataract surgery is crucial in promoting their independence and empowerment, reducing their anxiety, and improving their morale [10].

Visual impairment is not a direct cause of death, and the idea that visual impairment is a "normal part" of aging has been refuted in recent literature [13]. Exploring the patient's beliefs and attitudes about their ocular health is important as they appear to have a significant influence on decisions related to treatment. Becker's Health

Belief Model [14] suggests that people's willingness to modify their beliefs and change their behavior depends on evaluating the feasibility and weighing benefits against costs. Bandura's concept of self-efficacy suggests individuals must also believe they are capable of changing their behavior and feel sufficiently threatened by current behavior to become motivated to make a change [15]. Thus, effective communication skills, which include ensuring the patient's comfort, showing respect, maintaining eye contact, active listening and honesty, and positively responding to any questions asked are important as the basis for a therapeutic relationship.

Exploration of patients' perceptions of the likelihood of developing cataract blindness and the efficacy of consenting to cataract surgery and prescribed treatment is instrumental to preventing progressive vision loss and restoring sighted quality of life. The benefits of joining patient group meetings for additional support and information can also be suggested. Persistent experience of losing vision could lead to the onset of depression; encouraging self-belief and self-help are important to avert this by helping patients believe they are capable of changing their attitudes and behaviors [15]. It will also incentivize them to make the changes necessary to undergo surgery to regain quality of life.

3.2 Primary Open-Angle Glaucoma

Primary open-angle glaucoma (POAG) is a progressive disease in which the drainage angle is normal and open. Due to a degenerative process in the trabecular meshwork, it becomes blocked with extracellular material leading to reduced aqueous drainage and a rise in intra-ocular pressure (IOP). This compresses the optic nerve causing cell death and progressive gradual reduction in the visual field leading to tunnel vision [16].

POAG can cause severe visual impairment and even blindness and has a negative impact on quality of life. Visual disability, lifelong medical and surgical treatment, and the knowledge of having an irreversible potentially blinding condition tend to cause severe psychological stress in patients, leading to negative emotions such as anxiety or depression, poor self-image, poor psychological well-being, and reduced confidence in healthcare [17, 18]. Moreover, glaucoma patients are significantly at a higher risk of developing depression with age, female gender, and people on low-income, recently being identified as particular risk factors. Such patients have to cope with visual impairment, anxiety associated with blindness, long-term follow-up, and a heavy economic burden [19]. Modest correlations have been found between visual field losses and vision-specific dependency, role difficulties, social and emotional well-being, and mental health based on patient scores on the National Eye Institute Vision-Function Questionnaire (NEI VFQ-25) [19]. In the diagnosis and treatment of patients with glaucoma, ophthalmologists have often focused on clinical indicators, such as intra-ocular pressure (IOP), visual field (VF), visual acuity (VA), and adverse reactions to anti-glaucoma drugs, but they have paid little attention to their patients' quality of life and mental health. Research now suggests that physical activity is an important part of human lifestyle for maintaining and improving quality of life and mental health [19].

3.2.1 Psychosocial Care

Counseling is a key approach to providing psychosocial care for glaucoma patients.

Evidence is emerging that the goal of glaucoma treatment should not be limited to preserving the vision alone but also to addressing the psychological aspects and maintenance of the patient's well-being. It has been suggested that patient counseling should be available at the onset of diagnosis, and assessment should continue periodically. Importantly, raising the awareness of this condition within society would contribute overall to a valuable holistic approach to glaucoma [17].

Disease comprehension is often poor among patients, including those with glaucoma, causing psychological stress and feelings of despair and panic. Counseling patients about glaucoma disease can help alleviate this problem to some extent and should be started at the time of diagnosis by the treating clinician and continued on a periodic basis over the course of treatment. Patient awareness about the disease, the treatment options available, and the importance of treatment compliance and periodic motivation and follow-up are all extremely important in helping to alleviate psychological fear. Lifestyle counseling may also be of some value as a means of motivation to adhere to treatment and follow-ups. Research findings from a recent study concluded that comprehensive lifestyle counseling had succeeded in increasing medication adherence in patients with ocular hypertension and POAG at a 2–3 week follow-up (62.5% adherent at baseline and 78.9% adherent at follow-up). Almost one-quarter of the patients reached for follow-up who were previously nonadherent became adherent following lifestyle counseling. The comprehensive lifestyle counseling session was conducted by reviewing a pamphlet with pictures of recommended fruits and vegetables in correct portion sizes, stress control strategies, exercise frequency and duration, OTC vitamins, and tips for medication adherence [20]. The counseling categories were selected and utilized based on data suggesting that these variables may affect glaucoma onset and progression. Overall, lifestyle counseling may be seen not only as a driver to promoting adherence to treatment but also to pursuing a healthier lifestyle, thereby leading to improved intra-ocular pressure [20, 21].

Depressive symptomatology and decreasing motivation only intensify poor concordance with treatment with devastating outcomes for severe visual field and sight loss [22]. Helping patients therefore to come to terms with their emotions involves exploring expectations of better vision associated with treatment; it is necessary to dispel false hopes that either medical or surgical intervention will improve existing vision with reference to POAG. Once sight has been lost, it cannot be recovered. However, concordance with prescribed medical therapy is paramount in helping to maintain existing vision and further reducing visual field loss as part of an ongoing conservative approach to treatment. Healthcare professionals should provide the patient with opportunities to discuss any problems or concerns and subsequently offer advice and arrange for appropriate help and support to be given [22].

3.2.2 Practical Implications

Ongoing assessment is the basis for effective psychosocial care and management of practical implications. Some of the effects and implications of POAG are loss of contrast sensitivity and problems with glare and light sensitivity, which affect daily functioning, making activities such as driving or playing certain sports more challenging [23]. If there is a problem with night-time vision, the healthcare professional should urge patients to consider doing most of their traveling during the day. Sunglasses or tinted lenses can also be suggested to help with glare and contrast problems [23].

Falls are common among older adults with POAG and occur more frequently in those with greater visual field loss, particularly in the inferior field region. A history of rapid visual field loss in the inferior integrated binocular field has a major effect on the risk of falls in such patients [24]. Overall, falls can result in a decline in health status, daily functioning, lifestyle, and quality of life for glaucoma patients. Informal care and support networks are therefore important. The healthcare professional's responsibilities here are to help the older person to liaise with organizations such as the Royal National Institute of Blind People, the International Glaucoma Association, and local patient support groups, all of which can provide additional help and support to improve the quality of life. The Glaucoma Research Foundation will also provide information for newly diagnosed glaucoma patients and send free educational booklets both to the patient and a relative [23]. If driving is essential for the older person, safety to drive should be verified by an ophthalmologist and the Driver and Vehicle Licensing Agency guidelines should be followed [25].

Overall, the healthcare professional's key targets in the provision of psychosocial care and management of practical implications are therapeutic communication, psychological assessment using questionnaires, effective counseling skills including lifestyle counseling, patient education and information-giving about informal care and support networks for ongoing practical help, and support to promote medication adherence. Empowering patients with POAG is the basis for establishing independence and long-term control in the self-management of their ocular condition. This will help maintain a sight-related quality of life for as long as possible [23].

3.3 Age-Related Macular Degeneration

Age-related macular degeneration (AMD) refers to aging changes occurring in the macula in people aged 50 years and above. The condition is classified as either dry (atrophic) or wet (neovascular or exudative). Dry AMD is slowly progressive but gradual loss of central vision can substantially reduce the older person's ability to function and self-care [16]. Wet AMD is characterized by the growth of new blood vessels beneath the retina, known as choroidal neovascularization. It is aggressive in nature and can lead to severe sight loss in weeks or even days [16]. There is currently no cure for either type [16].

AMD can have profound consequences for both functional and psychological well-being, and there is growing and consistent evidence that depression is common among AMD sufferers. One study found that approximately one-third of the sample population reported clinically significant depressive symptomatology [26].

Anxiety is also prevalent among AMD patients [27]. Some of the main sources identified were fear of going blind from the intravitreal injections for wet AMD and concerns about treatment effectiveness, rather than trepidation around the pain factor. The study found that 17% of patients showed clinically significant levels of anxiety, and 12% had clinical levels of depression, with 56% reporting anxiety related to anti-VEGF treatment. Significantly, it also found that 89% of patients who showed anxiety and 91% who showed depression were not receiving psychiatric treatment.

The following case scenario illustrates the impact of AMD on an individual's quality of life and how the psychosocial and functional issues related to well-being need to be addressed.

Case Scenario

Female patient with wet age-related macular degeneration.

Pauline Smith, a retired 78-year-old single woman, with no immediate family, lives in rented accommodation in a high-rise block of flats. She used to work as a secretary and always enjoyed reading, cooking, and dancing in her spare time.

Over the past few weeks, she has experienced a significant decline in vision which has led to increased anxiety and loss of confidence about going out to socialize with old friends. She no longer reads newspapers resulting in disorientation and a sense of isolation from her immediate world. She finds it difficult to keep her flat clean and has recently had accidents in the kitchen such as burns and cuts when trying to cook meals. Consequently, she has resorted to living on sandwiches and snacks. Generally, she has also begun to feel low in spirits and depressed. She no longer enjoys doing anything and feels there is no pleasure left in her life.

After a visit to the optometrist, she was referred to the eye clinic where she was assessed and diagnosed with wet AMD in both eyes. Intravitreal Lucentis injections, every 4–6 weeks, were then prescribed to preserve her current level of vision.

3.3.1 Psychosocial and Functional Needs

In view of Pauline's situation, she will have been referred to the Older Persons' Mental Health Team (MHT) for assessment of her mental health and started on anti-depressant medication. A member of the MHT will then continue to monitor the effects of this medication. Counseling will also be offered. This is usually cognitive behavior therapy (CBT) which will be started about 4 weeks after commencing the anti-depressant therapy.

At the clinic appointment, a letter requesting an assessment for help with daily living needs will be sent to social services. A social services assistant then carries out an assessment of Pauline's needs and appropriate help and support required. Aids may be needed such as guards to prevent her from knocking over hot pans or to enable her to prepare food without cutting herself. If appropriate, help with major cleaning can be arranged through social services. The RNIB will be asked to offer her a lighted magnifying screen to enable her to read her newspaper or books. Audio books can also be offered.

An assistant occupational therapist will be allocated to help Pauline use the new safety equipment for cooking, and a charity can also be contacted to provide help to continue with dancing classes if this is wanted. A mental healthcare assistant (MHCA) can also provide help with weekly shopping and filling in any forms necessary to get extra funding needed as she may be on a limited income. The MHCA can also arrange a visit to a day center or drop-in center to have morning coffee and lunch and interact with other people.

3.3.2 Psychosocial Care

Quality time for the patient with AMD is essential to explain the treatment and allay any associated fears and anxieties. For the patient with dry AMD, there is no available treatment, but it is important to provide reassurance and education on the use of low-vision aids to promote independence and self-care. Clinic appointment follow-up is also beneficial to support well-being and exclude any other associated age-related ocular diseases such as glaucoma [28]. For the patient with wet AMD, a quiet environment is essential for breaking bad news especially if newly diagnosed with this condition. Explanation and reassurance are required about the importance of treatment, treatment options, and why intravitreal therapy (IVT) is appropriate for them [28]. In some instances, psychological support is required when the person has not met the criteria for commencing treatment. Sharing all appropriate information with the person's family and friends is also important as their understanding, help, and support will be needed. For people affected by macular disease, it can be frustrating and upsetting [1].

An explanation of the IVT procedure, what it involves, what to expect, and mentioning what the associated possible complications are, is important. Introducing an injection directly into the eye will provoke extreme anxieties, which persist throughout the pre- and post-injection stages [28]. Gaining insight into those anxieties and the older person's fears of going blind is integral to the healthcare professional's role. Exploration of feelings and thoughts is critical for patients' participation in their own care and future self-empowerment [22].

Wet AMD patients have approximately one-third of the ability of people with normal vision to perform everyday activities such as reading a newspaper, cooking, reading street signs, and walking down steps and curbs in low light. Similarly, they have less than half the ability of people with normal vision to perform everyday "distance" activities, such as recognizing faces, watching television, and taking part in outdoor activities [29]. Older AMD patients require more practical support and assistance to carry out daily activities than those with normal vision. The healthcare professional should therefore refer patients to the low-vision hospital clinic, the visually impaired team, and social services and the rehabilitation team to get advice about overcoming the problems associated with daily living, especially reading and writing, and enhancing visual rehabilitation [28]. With attention to health and exercise and the use of magnifying and other visual aids, patients with AMD can gradually work toward a new meaning in their lives and can then carry out their activities of daily living independently [30].

3.4 Charles Bonnet Syndrome

Charles Bonnet syndrome (CBS) refers to the presence of visual hallucinations experienced by individuals with reduced vision. Any underlying ocular pathology can precipitate CBS although the literature consistently identifies AMD as a risk factor and documents this syndrome as occurring mostly in people who have developed severe visual loss involving central vision in both eyes of which AMD is a cause [31, 32].

3.4.1 Psychosocial Care

Visual hallucinations in Charles Bonnet syndrome (CBS) can be a source of significant anxiety and emotional distress for people with sight loss [33]. Hallucinations can be simple, unformed flashes of light, colors or shapes, and geometrical grids and lattices. Other people report seeing disembodied heads, snakes, and other terrifying creatures [34]. Very recent research findings report exacerbation in experiences of this syndrome including increased frequency and more problematic visual hallucinations due to the social implications of COVID-19. Results also suggest that increasing social interactions, engaging in physical exercise and reducing news exposure may help alleviate symptoms in CBS. Such findings may also help change the focus of clinical practice as it is important for healthcare professionals to be aware of the risk factors for CBS and be conversant with strategies to promote effective patient self-management [34]. Clearly, CBS presents an important and challenging situation for the healthcare professional who needs to be aware of the unsettling and anxiety-provoking effects of visual hallucinations. Many patients will worry unnecessarily that there is something wrong with their mind and they are developing a mental illness such as dementia. Often, they are even afraid to tell their own family, friends, and doctors that they are experiencing hallucinations for fear of being misunderstood as a mental illness [35].

CBS is the result of the brain's reaction to visual loss [36], and the healthcare professional should explain to both patient and family that when sight is lost, the brain is not receiving as much information from the eyes as it used to; thus, the visual system does not process new images. The brain, however, can sometimes fill in these gaps by creating new images, patterns, or fantasy images. When this happens, these pictures are experienced as hallucinations [36]. Importantly, the healthcare professional should reassure and explain to the patient that these hallucinations are a natural experience, not a sign of mental illness. Naturally, older patients may not want to talk about their hallucinations because they are anxious about what they are seeing, or about what other people may think. Even though there is no cure for CBS, the patient should be encouraged to concede that this problem exists and talk to other people such as the GP or ophthalmologist about it, as this may provide some peace of mind for them.

It is helpful to make the patient and their family aware that CBS can last from days to years, but also to reassure them that for most people the hallucinations do eventually disappear. Initially, they occur unexpectedly and can last for just a few seconds or can be as long as a day or more. If the patient starts to experience hallucinations that are causing substantial distress, referral for professional counseling may be required. The Macular Society offers telephone counseling, and the RNIB's Emotional Support Service (ESS) also offers telephone support and counseling [36].

3.4.2 Controlling the Hallucinations

It is important for the healthcare professional to be aware of some suggested techniques for trying to make the hallucinations disappear [1]. These include using eye movements to lessen the impact and length of the hallucinations, which involves getting the person to imagine two points about a meter (3 feet) apart on a wall in front of them, standing about a meter and a half away. The patient then needs to look from one point to the other once every second, or faster, for 15–30 seconds, followed by a break of a few seconds. The eyes must be held open during these movements. If this fails, other techniques such as getting the person to close their eyes or look away from the image, switching on the room lights to create a brighter environment, or simply getting up and doing something else can also be tried. Such techniques can cause the hallucinations to disappear, but often they may continue. Research is underway to investigate whether the use of a noninvasive mild electric current, known as "transcranial direct current stimulation" (tDCS), can stop visual hallucinations. If successful, it will provide an alternative to medication [1].

3.5 Depression and Sight Loss

Arguably, of all the emotional reactions associated with ocular disease and sight loss discussed so far in this chapter, perhaps depression remains the most daunting for the patient and the most challenging psychosocial problem for the healthcare professional to recognize and manage effectively. Given the vulnerability of older adults with visual impairment and the increased rate of depression, the need for qualified healthcare professional support in the psychosocial domain is essential and overall adds significantly to the best available ophthalmic care, including treatment, within a holistic caring framework [37]. Evidence suggests that despite effective mental health treatments available for people with VI or blindness [38], more than half do not receive any mental health support for depression or anxiety [39]. However, different barriers for receiving treatment such as often experiencing a lack of knowledge about symptoms and treatment possibilities, and not wanting to rely on others, have been expressed by visually impaired and blind adults [39]. Further evidence suggests that the symptoms of depression and anxiety seem to be overlooked not only by visually impaired and blind adults themselves, but also by healthcare professionals such as eye care practitioners and low vision workers who often do not recognize depression in these two vulnerable groups of people. From the perspective of healthcare professionals, this may be due to their focus on physical health instead of psychological health [40, 41]. For eye care practitioners, a lack of confidence in their knowledge and skills appears to limit them in recognizing the symptoms of depression in adults with VI or blindness, thereby creating barriers to its management [41]. Evidence has also confirmed that adults with VI or blindness appear to encounter difficulties in being open about their mental health problems and sometimes even tend to deny psychological distress [41].

3.5.1 Psychosocial Interventions

Talking therapies such as counseling, cognitive behavior therapy (CBT), including stepped care interventions, and anti-depressant medication can be used to manage depression. Counseling and CBT can help people to work out how to deal with negative thoughts and feelings and make positive changes [42].

3.5.2 Counseling

A trusting and therapeutic relationship with the patient is essential as the prospect of facing sight loss is devastating [22]. Active listening and making positive responses can help ascertain the patient's feelings about blindness. Maintaining confidentiality and respecting the individual's privacy and dignity are essential because of the possible stigma and discrimination associated with depression; a quiet environment to make the patient feel comfortable and relaxed can help achieve this, thereby promoting more effective communication [22].

A positive attitude and providing appropriate information are essential to support the patient, especially when exploring the treatment options for depression and promoting the idea of an eventual recovery [43]. Patients feeling the need to express anger, fears, and other negative feelings about their sight loss and treatment should be encouraged during conversation. Patients should also be given opportunities to talk about difficult and negative feelings; it is emotionally liberating and therapeutic. Healthcare professionals must be able to understand the reasons for depression associated with sight loss to be able to help both patients and families [43]. Family members can often become depressed themselves when trying to cope with their loved one's anger, distress, and frustration. Self-sufficiency and self-esteem become diminished as the patient mourns the loss of his or her ability to see, and the family often shares this grief [44].

3.5.3 Cognitive Behavioral Therapy (CBT)

CBT is a psychosocial intervention that aims to improve mental health, and it is one of the most evidence-based psychological interventions for the treatment of several psychiatric disorders such as depression, anxiety disorders, somatoform disorder, and substance use disorder as well as stressful life situations such as sight loss, and many other clinical conditions [45]. It focuses on challenging and changing thoughts, beliefs, attitudes, and behaviors, improving emotional regulation and developing personal strategies that target solving problems [45, 46]. CBT is based on the concept of five interconnected areas, including situations, thoughts, emotions, physical feelings, and actions. It can help a patient to make sense of overwhelming problems by breaking such areas down into smaller parts. The CBT therapist can be any healthcare professional who has been specially trained in CBT, such as a psychiatrist, psychologist, mental health nurse, or GP. After an initial assessment period, the patient will begin to work with the therapist to analyze thoughts, feelings, and behaviors to determine how unrealistic or unhelpful they are and then provide help for changing them [46]. With reference to ophthalmic patients with AMD, modified cognitive-behavioral interventions have been used to improve depression and anxiety symptoms with some success. In one study, a single component of CBT, behavioral activation, in conjunction with low vision rehabilitation, was significantly more effective in preventing depression in patients with AMD compared with supportive therapy combined with low vision rehabilitation [47].

3.5.4 Stepped Care Interventions

Stepped care has been a recommended approach for treating mild–moderate levels of depression and anxiety. It provides patients with the least intensive interventions and then moves to more intensive services as required. In a multi-site randomized controlled trial testing the effectiveness of stepped care in ameliorating depression and anxiety in older adults with sight loss, findings pointed to significantly greater improvements in depressive and anxiety symptoms and vision-related QOL at the end of treatment. Older adults receiving stepped care were also less likely than those in the control groups to develop depression or anxiety disorder over a 2-year follow-up period [45]. Although less effective in preventing the recurrence of depression in people with pre-existing or past symptoms, it has demonstrated superiority to standard care in terms of cost-effectiveness and offered an advantage over traditional approaches in targeting mental health problems in adults with VI [44, 45].

3.6 Clinical Implications for Depression and Sight Loss

In summary, there may currently be a mismatch between the needs of visually impaired and blind adults and healthcare professionals' knowledge, skills, and attitudes related to being able to recognize the onset of anxiety and depression [40]. The important implications for clinical practice are firstly that healthcare professionals, including ophthalmologists, general practitioners, and low vision service workers, should be aware of the potential limitations adults with VI or blindness experience in recognizing and discussing mental health problems. Secondly, healthcare professionals' knowledge of the impact of VI on mental health should be increased via educational training. Consequently, this would enable the provision of information about depression and anxiety (psychoeducation) via suitable means for visually impaired and blind adults (verbally, digitally, or in Braille) to increase health literacy and reduce self-stigma [40]. Overall, this would enhance healthcare professional–patient communication around mental health issues, ultimately leading to the delivery of high-quality psychosocial care. The healthcare professional's role in supporting patients with VI or blindness will involve planning and designing care approaches to help such vulnerable people to live with their ocular condition. Additional training and education are therefore absolutely necessary to equip healthcare professionals to be able to address the mental health issues arising from ocular disease and sight loss at an early stage.

3.7 Conclusion

This chapter has focused on the emotional impact of sight loss due to ocular disease and its implications for quality of life, with particular reference to patients with cataract, POAG, and AMD. The role of the healthcare professional was discussed with reference to providing the appropriate psychosocial care in addressing the most commonly experienced emotional reactions following diagnosis of the ocular disease together with the practical implications of sight loss. In considering this role, the use of therapeutic communication and interpersonal skills was deemed to be pivotal to the delivery of effective psychosocial care. Meeting with the individual needs of patients with ocular disease and sight loss and their families, contributing to improving their quality of life through information-giving with particular reference to patient support groups and self-help groups, and providing overall psychological support including counseling and lifestyle counseling were seen as essential. In particular, the psychosocial support of people with Charles Bonnet syndrome and the ongoing management of their visual hallucinations was deemed as challenging. Similarly, challenging psychosocial aspects of care were discussed related to recognizing, addressing, and managing the onset of depression in patients with sight loss, taking prompt action to make appropriate mental health assessment and subsequent referrals for further professional psychosocial help and treatment, including the use of counseling and other psychosocial interventions such as cognitive behavioral therapy and stepped care interventions.

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Chapter 6: Conclusion

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This book targets all healthcare and allied professionals caring for people with ocular disease and sight loss. This includes groups such as clinical researchers, academics, patient representative groups, and students undertaking ophthalmic courses and courses in allied health disciplines. Initially, it revisits the main aims and key issues addressed in each chapter.

To recap, the main aims of this book were, firstly, to discuss the need for a theoretical basis for nursing practice to improve psychosocial care with reference to the emotional and psychosocial needs of patients with ocular disease and sight loss. Secondly, its aim was to raise awareness of the importance of the psychosocial needs of patients with ocular disease and sight loss with reference to relevant psychosocial theory and its application in practice.

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Thirdly, its aim was to discuss the role of healthcare professionals working within a multidisciplinary team to help provide integrated care. It was stressed that a holistic caring approach helps facilitate care to relieve emotional distress and promote quality of life for patients with ocular disease and sight loss. Psychosocial care is the culturally sensitive provision of psychological, social, and spiritual care through therapeutic communication, and such care is deemed to be extremely important within a holistic approach to practice. However, psychosocial care as such remains underestimated and under-researched in ophthalmic clinical practice.

The importance of the concept of theory is important to enhance practice. It was addressed with reference to selected nursing and psychosocial theories and models, and the value of addressing and applying such theories and models in practice was discussed with reference to the presentation and examination of case scenarios. Theories and models such as Roy's Adaptation Model and Orem's Self-Care Model and psychosocial theories such as Bandura's Social Learning Theory, Lazarus and Folkman's transactional theory of stress and coping, and Pender's Health Promotion Model were discussed to demonstrate the need for a theoretical basis for the specialist area of ophthalmic practice within the overarching framework of nursing. The conclusion was drawn that the integration of these theories was important for healthcare professionals in helping them to meet the specific psychosocial needs of patients with ocular disease and sight loss as well as the psychosocial needs of patients with general health conditions.

The analysis and application of theory were presented and demonstrated using the seven steps of theory suggested by Walker and Avant. This approach was seen to be helpful in determining the strengths and weaknesses of a theory and its potential use in practice, especially with reference to ophthalmic nursing practice. Moreover, using a standardized approach to analyze theories resulted in an increased understanding of the depth and breadth of such theories. Significantly, the knowledge gained from the analysis of theories can be applied to the care of individuals with ocular disease and sight loss. This emphasizes its value in identifying and addressing the psychosocial needs of patients and by providing the appropriate psychosocial care. Overall, the application of theory to psychosocial care will enhance the holistic approach to ophthalmic practice and also enhance its scholarly foundation.

The psychosocial impact of the concept of an altered body image for an individual with ocular disease and sight loss is seen to be of critical importance to address. Altered body image is defined as any significant alteration to body image occurring outside the realms of expected human development. Body image itself is defined as the picture of our body we form in our mind and one which can change during the course of a lifetime It is a diverse subject that involves perceptions, thoughts, and behaviors related to one's appearance. It is also strongly connected to the concept of self-esteem and, as such, is an important factor in an individual's ability to communicate confidently and take part in everyday social activities. Clearly, patients with disfiguring eye conditions such as thyroid eye disease, orbital exenteration for an orbital tumor, herpes zoster ophthalmicus, or squint may experience a profound psychosocial impact resulting in clinical anxiety, clinical depression, distress, stigma, and social avoidance. Thus, the healthcare professional has a key role to play in providing the psychosocial care and support needed to restore self-esteem using a holistic caring approach.

Self-esteem is at the center of the Price Model of Body Image Care, which is presented as an excellent framework to identify the psychosocial needs and plan the care and rehabilitation of patients with altered body image. It serves as a platform for restoring the confidence required to regain a desired quality of life. Linked to the concept of altered body image due to ocular disease and sight loss is the concept of stigma. Clearly, people with visual impairment and sight loss are at risk of stigma. They are vulnerable and can experience social isolation and reduced access to health and social care resulting in sadness, depression, stress, and anxiety. These factors can ultimately lead to self-pity and withdrawal from society. Thus, stigma imposed by the social environment may lead to self-stigma. Consequently, people with visual impairment and sight loss become conscious that they are perceived by society in a stereotypical way, which they accept, acknowledge, and believe that this is their real image. This negatively affects their self-attitude and obstructs undertaking actions to improve their situation in order to achieve goals in life including education and rehabilitation.

It is paramount that healthcare professionals are aware of stigma relating to sight loss. Ongoing training and education are essential to enable them to develop in-depth knowledge and understanding of the concept of stigma and to recognize stigma in people with visual impairment. Appropriate measures should be adopted to improve social contact, positive social interaction, and inclusivity, thereby improving positive self-image in people with visual impairment and sight loss. Healthcare professionals need to undertake a holistic patient care approach to contribute to reducing social and self-stigma, thus developing autonomy and improving the quality of life of people with sight loss.

Quality of life (QOL) has been defined as individuals' perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards, and concerns. Sight loss impacts the attributes of QOL including physical, social, and emotional well-being. The emotional impact of sight loss in reducing a person's QOL is well documented, with particular reference to older people. Vision loss and population aging have therefore become an important social issue worldwide, and improving QOL is one of the biggest challenges for healthcare professionals. Ocular diseases such as cataract, primary open-angle glaucoma, age-related macular degeneration, and Charles Bonnet Syndrome (CBS), the presence of visual hallucinations, can often affect QOL. AMD has been identified as a risk factor for this syndrome, which occurs mostly in people who have developed severe loss of central vision in both eyes of which AMD is a cause. The role of the healthcare professional is to provide the appropriate psychosocial care to address the most commonly experienced emotional reactions following diagnosis of the ocular condition alongside the practical implications of sight loss. Good therapeutic communication and interpersonal skills are instrumental to the delivery of effective psychosocial care. Moreover, the healthcare professional's ability to apply psychosocial theory to practice facilitates the process of regaining self-esteem and confidence sufficiently to enable the patient to return to a sense of well-being and acceptable QOL. Becker's Health Belief Model and Bandura's concept of self-efficacy were presented as useful psychosocial theories and tools to utilize in practice. Becker's Health Belief Model is useful when the healthcare professional is exploring the patients' beliefs and attitudes about their ocular health and when support and help are required to make decisions related to the benefits and costs of receiving treatment. Bandura's theory is useful for the healthcare professional to help patients to reach a state of self-belief about their own ability to change their behavior and cooperate with prescribed treatment. The successful outcome of the application of these theories is dependent on effective therapeutic communication.

The emotional reactions of sight loss due to ocular disease include stress, anxiety, low self-esteem, feelings of loneliness, depression, and sometimes suicidal thoughts and even suicide. Of all these emotional reactions, perhaps depression remains the most daunting for the patients and the most challenging psychosocial problem for the healthcare professional to recognize and manage effectively. Given the vulnerability of visually impaired older adults and increased rates of depression in this age group, the need for qualified healthcare professionals' psychosocial support is essential and adds to the best ophthalmic care available within a holistic caring framework. Healthcare professionals can utilize talking therapies such as counseling and cognitive behavior therapy, including stepped care interventions, to help people work out how to deal with their own fears, anxieties, negative thoughts, and feelings and then make positive changes.

In drawing conclusions from the chapter discussions, it appears that future perspectives and directions have emerged about the significance of psychosocial care for patients with ocular disease and sight loss within a holistic paradigm of care. Moreover, future perspectives on the role of the ophthalmic nurse and allied healthcare professionals have emerged as a basis for providing psychosocial care to facilitate emotional recovery and independence for the self-empowerment and self-management of patients with ocular disease.

The value of the use of theory to guide ophthalmic nursing practice and research is an important perspective for the future role of ophthalmic nurses and allied healthcare professionals. Unfortunately, the use of theory has been limited although it is clear that nursing departments and agencies often subscribe to nursing theory as part of their philosophy of care or nursing professional practice model. Ophthalmic nurses and healthcare professionals can learn and gain insight from published research studies which have used a theoretical framework for connecting the theory with the overall study aims, data collection and analysis, and the interpretation of findings. Incorporating theory into their research investigations, evidence-based practice projects, and quality improvement activities can strengthen and build nursing knowledge including the theories themselves. Importantly, the role of ophthalmic nurses and allied healthcare professionals must contribute to improving practice outcomes through observation, ongoing reflection, and critical evaluation.

An important future direction for ophthalmic nurses and healthcare professionals is for them to contribute to and participate in research activities in their practice environment. This would provide a platform for the sharing of their knowledge and clinical experiences through reflection on the psychosocial needs of patients with ocular disease and the effectiveness of the care given. This is tantamount to engaging in informal research activities, the experiences from which can then be utilized within a more formal research framework/structure. Although they may not be able to conduct primary research themselves initially, they can still become involved in researcher-led activities. Action research would be a crucial means of allowing ophthalmic nurses and allied healthcare professionals to become involved in the experience of collecting data based on meeting the needs of patients with ocular disease and sight loss. This would result in making a positive contribution to developing ophthalmic evidence-based practice within the domain of psychosocial care. The ultimate goal will be the formation of an international ophthalmic nursing research collaborative with a theoretical foundation that has the potential to advance the science of ophthalmic nursing. This will also represent a major achievement in bridging the theory-practice gap.

1 Summary

In summary, this text has endeavored to challenge all healthcare professionals to raise their awareness of the importance and value of psychosocial and nursing theory as a basis for addressing ophthalmic nursing practice as both an art and science within a holistic caring framework.

When ophthalmic nursing is viewed as an art and science, it can be utilized in a complementary way resulting in ongoing development and improvement of practice that benefits the care and treatment of patients with ocular disease and sight loss. Although more emphasis is given to the application of scientific principles, nevertheless, the greater need is to apply the principles of psychosocial theory to provide the necessary psychosocial care to meet the holistic needs of patients with ocular disease. It is not only the practitioners but the educators who will need to consider carefully the academic content relating to the psychosocial aspects of caring, with specific reference to ocular disease and sight loss. This same principle is equally applicable to all spheres of healthcare practice.

Index

S. Watkinson, S. N. Williamson (eds.), *Ocular Disease and Sight Loss: Meeting Psychosocial Needs*,
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