CHAPTER 1

INTRODUCTION

Background and significance of research problem

Visual impairment is a state of diminished visual acuity that ranges from low or partial vision to total blindness (Smith, 1997). According to the International Statistical Classification of Diseases and Related Health Problems in 1992 (Tenth Revision, WHO), low or partial vision means that the visual acuity with best possible correction is less than 0.3 and more than 0.05 in the better eye. Blindness is defined as a visual acuity that is not correctable to at least 0.05 in the better eye, or visual fields no greater than 10 degrees in its widest diameter regardless of visual acuity (World Health Organization, 1997). Practically, however, blindness would be better defined as the loss of useful sight that would enable a person to function normally in his or her environment (Smith, 1997).

There are two kinds of person with impaired vision: those who were born blind and those who develop some degrees of acquired visual impairment later in life. People who are born blind or develop blindness very early in life and who are raised as if they could see, and are neither overprotected nor rejected, frequently are self-confident

persons able to lead active productive lives (Phipps, 1993). Otherwise, when a sighted person is no longer able to see, his world changes, and he is required to make many adjustments.

It has been estimated that there are at least 42 to 50 million blind people in the world (Grimes, Scardino, & Martone, 1992). There are also an approximate of 110 million people with low vision with optimum correction (WHO, 1997). Experts believe that a number of blind person may as much as double by the end of the century (Grimes, Scardino, & Martone, 1992). There are many ocular disorders that can affect the sight. Major eye disorders including cataract, corneal impairment, injuries, glaucoma, retinal disease, strabismus, and amblyopia, can cause blindness (Grimes, Scardino, & Martino, 1992; Vader, 1992; Smith, 1997).

The American Academy of Ophthalmology Committee on Eye Care for the American People reports that in 1995 approximately one million Americans are legally blind, more than 11.4 millions are visually impaired because of chronic or permanent defects (deWit, 1998). Macular degeneration (16.8%), glaucoma (11.5%), diabetes retinopathy (10.1%), cataract (9.8%), and optic atrophy (4.3%) are major causes of blindness in the United States (Grimes, Scardino, & Martino, 1992; Vader, 1992).

Among the population of 1,266,838,000 in China (UN Population Division, 1999), the prevalence of blindness was 0.43% or 5.47 millions (Zhang, Zou, Gao, Di, & Wang, 1992).

It means that among blind persons worldwide, one-tenth were in China. Blindness results chiefly from cataract (41.06%), corneal diseases (15.38%), trachoma (10.87%), and glaucoma (8.80%); and the prevalence of low vision was 0.58% or 7.35 millions, of which the main causes were cataract (49.83%), ametropia/amblyopia (14.98%), trachoma (9.55%), corneal diseases (8.48%), chorioretinal diseases (6.27%) and others (10.89%). In Sichuan province, which is the largest province in China with a population of over 100 millions, the prevalence of blindness and low vision were 0.43% and 0.51%, respectively (Zhang, Zou, Gao, Di, & Wang, 1992).

The First Teaching Hospital of West China University of Medical Sciences (WCUMS), located in Sichuan province, is the most famous and biggest hospital in the southwestern China. It is a 1,100 bed hospital while 100 beds are for ophthalmic patients. The patients come from different parts of the southwestern area of China. According to the medical records, the number of patients with both eyes involved low vision or blindness is about 25 persons per month in 1998.

Sight is the person's most dominant sense. We live primarily in a visual world. It is estimated that 90 percent of our information reaches our brain by way of the eyes (Smith, 1997). For most part, the extent to which a person can independently perform the activities of daily living is related to an ability to see and interact with environment. Every person appreciates the value of vision and its contribution to learning, to using tools and devices, to

mobility, and to the quality of life (American Academy of Ophthalmology, 1987). From ancient time, blindness, like other handicaps, has been the cause of fear and rejection. It has always been one of the most feared of physical infirmities, and in many primitive cultures the sightless were denied any useful role in the family or tribe or even cast out to die (Smith, 1997). A recent poll found that the Americans fear of blindness more than other disorders except cancer (American Academy of Ophthalmology, 1995, cited in Smith, 1997). Therefore, the sight is considered as the most important sense. If one's sight is impaired, his normal living pattern relating to vision used will be disturbed. As a consequence, one's quality of life will also be affected.

According to Zhan (1992), quality of life is the extent to which a person's life experiences are satisfying in four aspects including life satisfaction, self-concept, health and functioning, and socioeconomic factors. Impaired vision can place somewhat impacts on the persons in those four dimensions.

Visual impairment burdens its victims with physical, emotional, psychosocial, and financial problems (deWit, 1998). Visual impairment affects the ability to perform basic day-to-day tasks in own home, in social settings, and on the job (Foxall, Barron, Dollen, Jomes, & Shull, 1992). Mobility or ability of the visual impaired persons to carry out activities of daily living may be restricted or at least modified (Phipps, 1993). With regard to physical aspect, the general health function of visual impaired persons is nearly

normal, but the visual function is impaired. However, the person wants to do something for himself/herself and for others, but he/she cannot do due to visual impairment. Therefore, visual impairment may also affect career options, job opportunities, and financial security (Phipps, 1993). They have to change their job or position that may result in decreased income. Some diseases which need to be treated constantly, such as glaucoma, may affect one's job and financial situation.

Visual impairment also affects the person's mental well-being. Smith (1997) reported that loss of vision provokes emotional response, such as frustration and annoyance. Some studies showed that low vision adults experienced a high level of loneliness (Jones, Freemon, & Goswick, 1981; Wulsin, Jacobson, & Rand, 1987) and also disturbed the person's self-esteem, self-confidence, and self-concept (Phipps, 1993). Allen (1989) found that depression, self-pity, and withdrawal were common among the persons with visual impairment.

Social aspect of visual impaired person's life is also affected including restriction of travel, decrease in participation of family and social activities, and unemployment (Lambert & Lambert, 1985). Visual impairment makes the persons having difficulty to maintain social contacts (Foxall, Barron, Dollen, Shull, & Jomes, 1994) and difficulty in performing effective communication with others (Fry, 1994), so loneliness and social isolation might develop.

All the abovementioned impacts can gradually reduce the person's satisfaction with life, thus affect the quality of life in some or all four dimensions. This requires person and the family in making adjustment to the changes and limitations.

Many factors have been considered as the contributing factors to quality of life. Some authors reported that gender and employment are the factors related to quality of life (Ferrans & Powers, 1993; Zhu,1997; Dibble, Padilla & Dodd, 1998). Income is another factor that affects the quality of life (Ferrans & Powers, 1992). Evan (1985, cited in Ferrans & Powers, 1993) stated education, race, marital status and social support had a significant influence on quality of life. Among many associated factors, social support was generally agreed as an obviously important one. Courten, Stevens, Crebolder, and Philipsen (1996) reported that social support has both stress bufffering and direct effect on a wide variety of outcomes including physical health, mental well-being, and social functioning.

Social support usually comes from peer, health staff, friends and family members (Drench, 1994). Family is considered as the primary social support group which plays an important role in promoting and protecting health (Pender, 1987). Most Chinese consider family as their most important source of support, especially when they are ill (Tong, 1990). Webb, Wrigley, Yoels and Fine (1995) suggested that family support improved quality of life of patients

with traumatic brain injuries indirectly by increasing functional independence. They also mentioned that brain injured patients with strong family support had less physical impairment, which directly improved quality of life, and indirectly improved quality of life through increased likelihood of employment and also reducing the need for rehabilitation resulted in improving functional independence.

For visual impaired persons, the social support from family is especially important. Family members can provide support that help persons coping with daily living activities, health problem, financial and mental problem. Family support was defined by Procidano and Heller (1983) as perception that his/her needs for support, information and feedback are fulfilled by family members. When family members' needs were met, they feel satisfication with life.

Although family support and quality of life are so important to persons with visual impairment, unfortunately, no literature can be found in describing the status of family support and quality of life and exploring the relationship between these two variables among Chinese persons with visual impairment. Nurses are the people who are responsible for taking care of the persons and helping them to enhance their quality of life. Therefore, this study was designed to describe the family support and quality of life, and to examine the relationship between two variables among Chinese visual impaired persons. The findings from this study provided some information to guide nurses in

making clinical decisions and planning to help facilitating the nurses and family members in taking actions to improve the quality of life of visual impaired persons.

Objectives of the study

The objectives of this study were:

1. To describe the family support among visual impaired persons;

2. To describe the quality of life among visual impaired persons; and

3. To examine the relationship between family support and quality of life among visual impaired persons.

Hypothesis

There is a relationship between family support and quality of life among visual impaired persons.

Scope of the study

The study were conducted among visual impaired persons who attend ocular outpatient clinic in the First Teaching Hospital of West China University of Medical Sciences in Chengdu, P. R. China, during November 1999 to January 2000.

Definition of terms

Family support refers to the person's perception that his/her needs for assistance are fulfilled by family members including parents, siblings, and spouse, children and close relatives. It was measured by Modified Perceived Social Support from Family Scale (MPSS-Fa)(Zhang, 1997).

Quality of life refers to self-evaluation of visual impaired persons in four domains including life satisfaction, self-concept, health and functioning and socioeconomic factors. It was measured by Modified Quality of Life Questionnaire (MQOLQ) modified from Zhang's Quality of Life Questionnaire (1998) by the researcher.

Visual impaired persons Refers to those adult individuals having visual disorders attending the ocular outpatient clinic with visual acuity of 0.3 or less, or visual fields of 10 degrees or less in the better eye, with best correction for at least half year.