CHAPTER 2

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK

Literature pertaining to the visual impairment and its impact on persons, family support, and quality of life were reviewed and the conceptual framework was presented in this chapter.

Literature review

The literature review for this study included the following:

1. Visual impairment and its impact on persons;
2. Family support;
3. Quality of life; and
4. Relationship between family support and quality of life.

Visual impairment and its impact on persons

Within the past two decades, there have been many new developments in the treatment of a number of potentially blind diseases. These new surgical techniques and medical treatment offer opportunities for eyesight recovery and preservation to people (deWit, 1998). However, some incurable ocular diseases and some end-stage ocular diseases can still cause low vision or blindness later in life. According to the report of World Health Organization (1997), low or partial vision was identified as the visual acuity is less than 0.3 and more than 0.05 in the better eye with best possible correction, and blindness was defined as a visual acuity that is not correctable to at least 0.05 in the better eye, or visual fields of 10 degrees or less in its widest diameter regardless of visual acuity. This impaired vision can place some effects on person's life.

Visual impairment affects persons in various aspects. Persons who have low vision still have some amount of useable vision, but their visual functioning is impaired and interferes with their ability to carry out desired task (Fletcher, 1993, cited in Lampert & Lapolice, 1995). Their mobility and ability to carry out activities of daily living may also be restricted or as least modified. A study in exploring the relationship between visual impairment and functional dependency among nursing home residents indicated that visual status is an independent significant predictor of activities of daily living and functional dependency (Horowitz, 1994). Limitations in the range and variety of experiences are related to the fact that person who cannot see must use touch and kinesthetic to gain knowledge of the world (Phipps, 1993). Objects too big or too small to handle are not perceivable. Many visual impaired persons feel that the restriction in mobility resulting from blindness is its most serious effect. Blind persons cannot move about as quick, secure, or easy as sighted persons can. Familiar hobbies that require vision, such as reading, sewing, or crafts, may no longer be possible (Phipps, 1993).

Visual impairment and restriction in activities can also cause some psychological problems, such as anxiety, powerlessness, grieving, depression, frustration, and loss of confidence (Frost, Sparrow, Durant, Donovan, Paters, & Brookes, 1998,). Loss of vision may affect individual’s self-esteem and the ability to interact with others and with environment (Phipps, 1993; Foxall, Barron, Dollen, Shull, & Jones, 1994), effective communication with others is also affected, and a sense of isolation may develop (Fry, 1994; Smith, 1997). The adult who becomes blind fairly rapidly usually has greater difficulty adjusting to the handicap. The impairment may also cause decreasing in self-confidence and self-concept. Moreover, loss of vision can cause emotional reactions such as denial, anger, guilty, resentment, hopelessness and loneliness (Phipps, 1993). These strong emotional feelings interfere with the blind person's ability to plan new ways of accomplishing tasks of living. The ability to cope with the loss depending on the extent and duration of the handicap, the age at which it occurs, how the person had successfully adapted in the past, and the presence of available support system, especially from family (Phipps, 1993).

Bernbaum, Albert, Duckro and Merkel (1993) reported that visual impairment was a major stressor in the spousal relationship. Blindness may also influence the person's ability to remain independent, to feel socially adequate, or to feel that he or she is a contributing member of society (Phipps, 1993). Therefore, he or she may have problems of social isolation and social disengagement. On the other hands, visual impairment may affect career options and job opportunities, and also financial security (Phipps, 1993).

In summary, person with visual impairment experiences many problems that can affect physical, psychological, socioeconomic well-being, and eventually influence quality of life globally. Some factors might affect the person's ability to cope with the impacts of visual impairment, one of the factors is the presence of available support system, especially available from family (Phipps, 1993).

Family support

The definition of family support, significance of family support, measurement of family support, and family support of visual impaired persons were reviewed in this part.

Definition

The family is an active operating system that functions as a unit. It is considered as the primary social support group which plays an important role in promoting and protecting health (Pender, 1987). Meister (1991) stated that much of what that the family contributes to members could be called social support. Therefore, family support is often discussed within the context of social support. Moreover, the content of definition of family support in the literature is similar to that of social support except the sources of support (Brillhart, 1988; Cobb, 1976; Procidano & Heller, 1983). Hence, we should review for the clear meaning of social support before understanding the concept of family support.

Social support is a multidimensional construct. The concept of social support has emerged in recent years as a major psychosocial variable in health-related research. However, there is no universal accepted definition or conceptualization of social support. House (1981) defined social support as composed of four subconcepts: emotional support (esteem, affect, trust, concern, listening), appraisal support (affirmation, feedback, social comparison), informational support (advice, suggestion, directions, information), and instrumental support. Tilden and Weinert (1987) claimed that social support refers to the psychosocial and tangible aid provided by the social network including family, friends, neighbors, co-workers, and others, which is received by a person.

The definition provided by Cobb (1976) stated that social support is provision of information that leads people to believe that they are cared for, loved, esteemed, valued, and members of a network of mutual obligation. Cobb's definition of family support is very similar to that of his definition of social support, except the different supportive source. Cobb (1976, cited in Caldwell, 1988) defined family support as information leading the family members to believe that he/she is cared for, loved, and valued. Either definition of family support or social support emphasized emotional impacts of support on the support person.

Brillhart (1988) also provided the definition of family support. He defined family support as the perceived social support encompassed four aspects in terms of physical care, economic support, emotional support, and social support including communication, response, and sense of belonging.

Procidano and Heller (1983) defined family support as the perceived needs for moral and emotional support as well as the need for information, and feedback fulfilled by family. They indicated the family support as the social support from family members.

In summary, family support is regarded as an aspect of social support. The perceived social support from family can be called family support. Frequently, the definition of family support is similar to those of social support except the resources of support. Family support is provided by family members. The definition provided by Procidano and Heller was used in this study.

Significance of family support

The quality and availability of social support are important parts in person's life. Some authors suggested that social support may have a protective function, serve as a stress-buffering or moderating role in health maintenance, and be related to positive health outcomes (Cobb, 1976; Kaplan, Cassel, & Gore, 1977; Dean & Lin, 1977; Kahn &

Antonucci, 1981; Broadhead, Kaplan, & James, 1983, cited in Lindsey, 1992).

Bloom and Spiegel (1984) reported that social support could be a good moderator to protect people in crisis from a wide variety of pathological status and help patients justifying their stressful situation. According to Cobb (1976), the social support could reduce the amount of medication required, accelerate recovery, and facilitate compliance with prescribed medical requirements. White, Richard, and Fry (1992) found that social support was associated with the process of adjustment to chronic illness. The greater the perceived social support, the better the psychosocial adjustment to illness in 193 chronic disease patients in their study.

Cohen (1988) specified the possible mechanism of social support as (1) biological process model in which increases support is presumed to result in suppression of neuroendocrine and hemodynamic response and increasing immune competence; (2) stress-buffering model is presumed that social support may alleviate the impact of stress by providing a solution to the problem, reducing the perceived importance of the problem; and (3) main-effect model is in terms of providing services or information regarding the benefits of behaviors that positively influence health and well-being, and by social integration to increase feeling of self-esteem, self-identity, and control over one's environment.

Since the family support can provide multiple support including physical care, economic support, emotional support, and social support in terms of communication, response, and sense of belonging (Brillhart, 1988), family has powerful influence on adjustment of patient. As a result of visual limitations, the person may need help with activities such as driving, reading, doing hobbies, daily living, and work. The ability to perform these activities with assistance will bring pleasure and reinforce feeling of personal worth and ability (Staab & Hodge, 1996). Jassak (1992) reported that the cancer patients who received minimal family support experienced more difficult in adjusting to the disease and treatment.

In summary, family support can affect the client's health, facilitate better psychosocial adjustment, and has positive influence on well-being.

Measurement of family support

Since family support was considered as social support from family, the instrument for measurement of social support is often used to measure family support. There are various instruments for measurement of family support.

Family Social Support Index (FSSI) developed by Fink (1995), based on Kahn and Antonucci's (1980, cited in Fink, 1995) definition of social support was used to measure social support from relatives, friends and community, which is 35-item, four point scale. Respondents are asked to rate their agreement with each item on a scale from 1 (strongly disagree) to 4 (strongly agree). The initial internal reliability was obtained (r =. 91) in a pilot test with a sample of 54 individuals.

The Perceived Social Support from Family Scale (PSS-Fa) was developed by Procidano and Heller (1983) to measure the family support in 222 undergraduates studying at Indiana University. It based on the definition of the family support as the extent to which an individual believes that his/her needs for support, information, and feedback are fulfilled by family members (Procidano & Heller, 1983). The original PSS-Fa consists of 20 items referred to feelings and experiences which occur to most people at one time or another in their relationships with members of their families. The response options are "yes", "no", or "don't know". The total score ranges from 0 to 20 with the higher score presenting more support. Procidano and Heller (1983) reported that internal reliability of PSS-Fa is high, with a Cronbach alpha value of .90. The test-retest reliability has been shown to be between .80 and .86.

Zhang's (1997) Modified Perceived Social Support from Family Scale (MPSS-Fa) was modified from the PSS-Fa (Procidano & Heller, 1983) to study family support among breast cancer patients. In the MPSS-Fa, Zhang (1997) deleted the answer option of "don't know" because the subjects might give more responses of it that could not be included in her study. Five items from the PSS-Fa were also deleted by Zhang (1997) because they were not suitable to assess family support. The MPSS-Fa was a 15-item questionnaire with the answer in a "yes" or "no" format. There are five negative items. Reliability of this instrument in Chinese version was tested among ten breast cancer patients in China using Kuder-Richardson 21 (KR-21). The internal consistency reliability coefficiency was .75, which considered as acceptable leval (Polit & Hungler, 1991).

For measuring the family support of visual impaired persons, the MPSS-Fa was used in this study. Because the aspects included are congruent with the feature of visual impaired persons.

Family support in visual impaired persons

Based on literature review,studies about family support in visual impaired persons cannot be found. However, a few studies on social support among those persons and family support in other groups of chronic patients were available and presented.

A study in investigating marital status, social support and loneliness in 87 visually impaired elderly persons conducted by Barron, Foxall, Dollen, Jones and Shull (1994) showed that family members provided most of the emotional support for married and widowed persons. Married persons received most of their family support from spouses and children. The widowed cited other family members as support sources more frequently than did the married. Family support for never-married persons came primarily from nieces and nephews.

Another study conducted by Brillhart (1988) on family support in 143 disabled adults indicated a significant difference in the quality of support offered by different family members. The parents offered significantly more support to the disabled adults. The support offered was focused on meeting economic, emotional, social, and physical needs. The parents of the adult disabled were identified as key persons for patient-family educational, sessions, support or discussion groups, and family counseling. The positive family support for the disabled includes reestablished roles, empathy, and for the identified needs. The disabled persons often relied on family members for physical care, social contacts, emotional support, and financial aid (Brillhart, 1988).

In summary, family provides emotional, economic support and assistance to meet the needs of their family members. The major support sources are spouse, parents and children.

Quality of life

The definition of quality of life, dimensions of quality of life, measurement of quality of life, and quality of life in visual impaired persons were reviewed and presented in this part.

Definition

The concept of quality of life is defined differently by different people. Quality of life has been defined in purely objective terms by measuring such items as income, housing, physical function, and purity of air (Frank-Stromborg, 1992). Contemporary sociologists and psychologists have described quality of life in terms of individual's aspirations and expectations in life, and how well those aspirations and expectations are fulfilled (Anderson & Burckhardt, 1999). Other authors have focused on the subjective dimensions by investigating individual aspirations, attitudes, and perceptions (Patreck, Bush, & Chan, 1973; House, Livingston, & Swinburn, 1975; Compbell, 1976, cited in Frank-Stromborg, 1992). Therefore, the definition of quality of life is various. According to Young-Graham and Longman (1987), quality of life is the degree of perceived satisfaction with present life circumstances. Ferrans and Powers (1992) defined quality of life as a person's sense of well-being that stems from satisfaction or dissatisfaction with the areas of life that are important to him/her. This definition addressed the fact that people's values caused various aspects of life to have varying impact on their quality of life (Ferrell, 1990).

Farquhar (1995) categorized the definition of quality of life in three types: 1) global definition; 2) component definition; and 3) focused definition. The global definition includes physical function; symptoms from disease and/or treatment; occupational and social interaction; and psychological parameters, including mood and some overall assessment of well-being, such as happiness or satisfaction (Smart & Yates, 1987). George and Bearon’s definition (1980, cited in Farquhar, 1995) is a sample of component definition. Their definition of quality of life includes four dimensions, two of which are objective and others are reflected in the personal judgment of the individual. The objective dimensions are general health and functional status, and socioeconomic status. The personal judgment or subjective dimensions are life satisfaction and related measures, and self-esteem and related measures. The third type definition refers to only one or a small number of the component of quality of life. The most common form of this definition refers only to the components of health/functional ability (Farquhar, 1995). Therefore, quality of life is a multi-faceted phenomenon and any measures taken during treatment purporting to improve the quality of life must address the impact that disease and its treatment has on a variety of dimensions, not simple physical functioning (Fallowfield, 1990).

Dimensions of quality of life

There is no standard for describing the dimension of quality of life. Frank-Stromborg (1992) listed some objective and subjective dimensions as follows: 1) subject's opinion of quality of life or life satisfaction; 2) socioeconomic status including occupation, education, income, and/or financial status; 3) physical health including activity level and/or physical symptoms; 4) affection; 5) perceived stress; 6) friendship including social support; 7) family including children; 8) marriage including sex; 9) achievement of life goals; 10) satisfaction with housing and neighborhood; 11) satisfaction with city and nation; 12) satisfaction with self including self-esteem; and 13) depression, psychological defense mechanism, and ability to cope.

Many authors described quality of life in various dimensions. Hutchinson (1979, cited in Dean, 1985) identified physical, social, and emotional factors as three dimensions of quality of life. Most authors identified the dimensions of quality of life in four aspects, but the content is various due to differences in definition.

Ferrans and Powers (1992) identified the four dimensions of quality of life as life satisfaction, self-esteem, health and functioning, and socioeconomic status. They refer self-esteem as an individual's evaluation of self worth and consider life satisfaction to be the crucial indicator of subjective quality of life.

Other authors also regarded that quality of life including four dimensions in terms of health and functioning, socioeconomic, psychological, and family factors (Ferrans & Powers, 1985; Hicks, Larson, & Ferrans, 1992).

There are five dimensions of quality of life that were described by Ware (1984, cited in Dean, 1985). He identified the five dimensions as disease, personal functioning, psychological distress/well-being, general health perception, and social role functioning. Flanagan (1982) described five dimensions of quality of life in terms of physical and material well-being, relation with other people, participation in social, community and civic activities, personal development/fulfillment, and recreation.

Zhan's (1992) quality of life also includes four dimensions, which are life satisfaction, self-concept, health and functioning, and socioeconomic factors. Life satisfaction refers to life as a whole rather than to specific domains of life experience. Because of its global nature, domain-specific measures of satisfaction are an alternative approach to the use of global measures. Self-concept is defined as the composite of beliefs and feelings that one holds about oneself at a given time. It focuses on the individual's assessment and evaluation of himself/herself as an object in the life experience. Concept of health and functioning has been operationalized in terms of activity in daily life and mobility or absence of disease. Socioeconomic factors have been assessing subjectively in terms of perceived adequacy of income and satisfaction with financial resource.

In conclusion, the dimensions of quality of life are varying associated with different researchers and population according to the definition. Zhan's (1992) four dimensions cover the quality of life of persons with visual impairment. In present study, the researcher used Zhan's four dimensions to study quality of life in visual impaired persons.

Measurement of quality of life

The assessment of quality of life is still an evolving area of clinical research. The researcher desiring to measure this area must consider multiple issues and choices of instrument selection. However, the choice of selection will depend on the goal of the research, as well as pragmatic consideration. There are various instruments being used to assess quality of life from different views.

Early attempts to measure quality of life in patients focused on one dimension of the patient's life - the ability to perform activities of daily living (ADL). Karnofsky and Burchenal (1949, cited in Frank-Stromborg, 1992) developed a scale that rates physical activity from 1 to 100 percent in increments of 10 percent. The Zubrod Scale (a scale of 0 to 4 in increments of 1) evaluates the ability of the patient to remain ambulatory and to perform activities of daily living (1962, cited in Frank-Stromborg, 1992).

Ferrans and Powers Quality of Life Index (QOLI) was developed to measure the quality of life of healthy people as well as those who are experiencing illness (Ferrans & Powers, 1985). This instrument has 35 items that assess 18 areas including life goals, general satisfactions, stress, and physical health. The instrument consists of two sections. One section measures satisfaction with various domains of life, and another section measures the importance of the domains to the subject. This approach to quality of life measurement is unique among all the tools.

Another approach for measuring quality of life is to measure satisfaction with life. Cantril's Self-Anchoring Life Satisfaction Scale (1983, cited in Frank-Stromborg, 1992) was designed to measure a general sense of well-being. The subjective scale asks the subject to identify the best possible life he could imagine and define the worst possible life he could also imagine. These two extremes are related to a ladder with the best possible life on rung 10 and the worst possible life on rung 1. Subjects are then asked to indicate where on the ladder they would place themselves 5 years ago, at present, and 5 years hence. The same procedure is used for assessing health status. This approach for measuring quality of life has been used successfully with patients undergoing dialysis or coronary revascularization or with severe osteoarthritis (Laborde, & Powers, 1980, cited in Frank-Stromborg, 1992; Penckofer & Holm, 1984).

Spitzer assessment tool (1981, cited in Goodinson & Singleton, 1989), used a unique Apgar-like' scale, was used to measure quality of life. Five dimensions namely activity, daily living, health, support, and outlook were investigated. Visual (Linear) Analogue Scales (VAS) was used for quality of life assessment. This form of measurement utilizes line 0-100 mm long, denoting a continuum of dimensions in emotional, experience, with anchor words or phrase marking the extremes.

Quality of Life Questionnaire (QOLQ) developed by Uppalabut's (1994) based on Zhan's concept (1992) to measure quality of life of 120 leukemia patients in Thailand. The validity and reliability were approved. The Cronbach's alpha was .85. It is a 60-item, five-point rating scale which included four dimensions in terms of life satisfaction, self-concept, health and functioning, and socioeconomic factors. It consists of 15 items in each dimension. Zhang (1998) modified the QOLQ from Uppalabut's QOLQ (1994) to study the quality of life in chronic renal failure patients who receive hemodialysis. To ensure it was appropriate to her subjects, Zhang deleted eight items and relocated some items into appropriate categories according to experts' suggestion. The MQOLQ is a 52-item, five-point rating scale which includes four domains: life satisfaction (10 items), self-concept (16 items), health and functioning (16 items), and socioeconomic factors (10 items). Fifteen of them are negative items. The scoring of the positive items is 5 as very much, 4 as much, 3 as moderate, 2 as little, and 1 as very little. The negative items are reversed scores. The possible highest score of the MQOLQ is 260(5 × 52) that represents the best quality of life; the possible lowest score is 52 (1 × 52). The reliability of the Zhang's MQOLQ was measured by Cronbach's alpha. The internal consistency reliability coefficiency was .75.

In conclusion, there are various instruments to measure quality of life. When deciding which instrument is appropriate, the congruency between what variables the researcher wants to measure and what dimensions an instrument has been contained should be considered. In present study, there was no completely and properly existing instrument for measuring the quality of life of visual impaired persons. Therefore, the researcher used the MQOLQ to measure quality of life which was modified from Zhang's QOLQ (1998) because it was more congruence with this study than others.

Quality of life in visual impaired persons

There are few studies on quality of life among visual impaired persons. Recently, quality of life related to vision has been considered, particularly with respect to cataract surgery. There is also increasing interest in quality of life issues in person receiving corneal surgery, glaucoma, cytomegalovirus retinitis, blind rehabilitation and blepharoptosis surgery (Drummond, 1990; Scott et al., 1994, cited in Frost, Sparrow, Durant, Donovan, Peters, & Brookes, 1998). The results from many studies showed that improved function after cataract surgery was associated with better health-related quality of life, suggesting that age-related declines in health may be attenuated by improvement in visual function (Mangione, Philips, Lawrence, Seddon, Orav, & Goldman, 1994; Desai, Reidy, Minassian, Vafidis, & Bolger, 1996, cited in Frost et al., 1998).

Scott, Schein, West, Bandeen-Roche, Enger, and Folsten (1994) reported that visual acuity was associated with functional status /quality of life. And the ophthalmic patients were at high risk for decreased functional status/quality of life compared with the persons with normal visual acuity and unknown ocular disease.

Lee, Spritzer, and Hay (1997) conducted a study in 1,642 persons aimed to determine the impact of blurred vision on functional status and well-being. They found the unique impact of blurred vision on role limitation due to physical health problems was significantly greater than the impact of hypertension, history of myocardial infarction, type II diabetes mellitus, indigestion, trouble urinating, and headache. Blurred vision also had a significantly greater negative impact on energy than type I diabetes mellitus, on social function than indigestion, and on physical functioning than trouble urination. Therefore, having blurred vision has a detectable and significant impact on functional status and well-being.

A study conducted by Williams, Brody, Thomas, Kaplan, and Brown (1998) in 86 elderly adults with age-related macular degeneration (AMD) legally blinded in at least one eye to demonstrate the impact of AMD on quality of life, emotional distress, and functional level. It showed that persons with AMD experienced significant reductions in key aspects of daily life. Their ratings for quality of life (average Quality of Well-being Scale score = 0.581) and emotional distress (average Profile of Mood States total score = 65.36) were significantly worse than those for similarly aged community adults and were comparable with those reported by people with chronic illness (e.g., arthritis, chronic obstructive pulmonary disease, acquired immunodeficiency syndrome, and bone marrow transplants).

Patients with AMD were also more likely than a national sample of elderly individuals to need help with daily activities.

In conclusion, quality of life is a person's subjective sense. The quality of life of visual impaired persons had been affected by the poor sight. Comparison with other normal elderly and persons with chronic disease, the visual impaired persons seem to be at a lower level of quality of life. Thus, nurses should take some actions to improve visual impaired person's quality of life in various domains.

The relationship between family support and quality of life

Based on literature review, there is no study reported for exploring the relationship between family support and quality of life among visual impaired persons. However, there are few studies concerning the relationship between social support and quality of life among other group of patients.

Friedman (1993) conducted a study to identify the relationship between social support sources and psychological well-being in 80 older women with heart disease. It was found that women without spouses perceived less tangible and emotional support and resulting in more decreased psychological well-being than women with spouses.

Tell, Mittelmark, Hylander, Shumaker, Russell, and Burkart (1995) conducted a study on social support and health-related quality of life in 256 black and white dialysis patients. They found that the higher they perceived social support, the better they reported and observed functional level. Good social support was associated with fewer limitations in leisure time activities which resulted in better life satisfaction. A large social network was related to better feelings regarding life and to better life satisfaction.

Courten, Stevens, Crebolder and Philipsen (1996) studied the quality of life and social support with a longitudinal design in 51 newly diagnosed cancer patients and followed for one year. The result showed that emotional support was positively related to quality of life ($p <.01$). They also found a tendency that the patients with deterioration in quality of' life perceive a large decrease in emotional support than patients with a positive course. The amount of perceived instrumental support did not change significantly.

A descriptive correlational study was conducted by Zhang (1998) to ascertain the relationship between family support and quality of life among 60 Chinese hemodialysis patients. The result showed that there was a significantly positive relationship between family support and quality of life($r = .4379$, $p < .001$). Liu (1999) also reported that there was a significant positive relationship between social support and quality of life ($r = .577$, $p <. 01$) among 60 renal transplant patients.

In summary, the literature provided the information that there is a positive relationship between social support and quality of life. However, no studies were found to explore the relationship between family support and quality of life in visual impaired persons. Therefore, it is worth to examine the relationship between family support and quality of life among persons with visual impairment.

Conceptual framework

The conceptual framework of this study is based on Zhan's (1992) quality of life concept and Procidano and Heller's (1983) definition of social support from family.

As previously mentioned that the persons with visual impairment face with many problems in different aspects due to impaired vision itself and its impact. These problems could affect persons' physical, psychological, and socioeconomic aspects. All of those can affect the persons' life satisfaction, self-concept, health and functioning, and socioeconomic factors.

Family support has direct effect on a wide variety of outcomes including physical health, mental well-being, and social functioning. Family is considered as a natural support system which could be considered as one major environmental factor that support family members in order to deal with the stress. It can also be considered as the primary social network in the environment that can provide relevant assistance to help the visual impaired persons. Thus, the visual impaired person's well-being is possibly improved by family support.