Abstract of dissertation entitled

“A Self-management Programme for Older Adults with Age-related Macular Degeneration (AMD)”

Submitted by

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Age-related macular degeneration (AMD) causes vision impairment which is not recoverable under existing treatment options. It has been a major leading cause of blindness in the aged population. To ameliorate the self-care ability for AMD patients, educational interventions to mediate negative impacts of the disease on quality of life have become a research interest. Current practice in the proposed Hong Kong setting, Elderly Health Centre A and Elderly Health Centre B, depends on nurses giving general advice which is lack of scientific support and non-specific to AMD. Purpose of this dissertation is to translate the best evidence to practice for improving the care of older adults with AMD in the proposed setting. Evidences showed that self-management education programmes were effective in improving emotional distress and self-efficacy. Electronic searches located 9 relevant RCTs of high level and methodologically strong evidences. Data was extracted into tables of evidence. Data summary and synthesis was presented. Assessment on the implementation potential indicated that the SEP was worth to try in the local setting. Twelve recommendations for the practice guidelines of SEP were presented and a communication process to facilitate the change in a top-down approach was introduced. A pilot study plan in Centre A followed by a main study in Centre A and Centre B was presented. A total of 98
elderly patients with AMD will be recruited as 10 SEP groups. Approximately 1.8 years will be used to finish the main study. Outcomes will be measured at the 6th week follow-up. ‘Emotional distress’ will be measured as primary outcome and ‘self-efficacy’ will be measured as secondary outcome. ‘Client satisfaction’, ‘staff satisfaction’ and the ‘utilization rate of the innovation’ will also be assessed in evaluation. A two-tailed paired (one-sample) t-test will be adopted for analysis, with a 95% confidence interval. The basis for effectiveness for the outcome measurements and basis for adoption of the clinical guidelines were stated. Adoption of the developed guidelines in the local setting will optimistically improve the substantial clinical outcomes for AMD patients, mediating the negative impacts of vision impairment or vision loss on their quality of life.
A Self-management Programme for Older Adults with
Age-related Macular Degeneration (AMD)

by

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the degree of Master of Nursing
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Declaration

I declare that this dissertation represents my own work, except where due acknowledgement is made, and that it has not been previously included in a thesis, dissertation or report submitted to this University or to any other institution for a degree, diploma or other qualifications.

Signed _________________________________

Young Ping
Acknowledgements

I dedicate this dissertation to my Heavenly Father. HE has kept my families, my close friends and me under HIS shelter during the period of my Master study. I deeply felt that my weight be taken up by HIM at times HE answered my prayers with grace and mercy. I take this dissertation, which is also affirmatively accomplished with HIS kindness love, to present my deepest gratitude and reverence to my Heavenly Father.

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Chapter 1: Statement of the Problem

Age-related macular degeneration (AMD) has been a major leading cause of permanent blindness in the aged population over 60's (Department of Ophthalmology and Visual Sciences [OVSD], 2001). Unlike cataract, AMD causes vision impairment or blindness which is not recoverable under existing medical or surgical treatment options. Ageing, however, is a major factor strongly linked to AMD. As the population ages, the global increase in the number of elders living with AMD is predicted to be dramatic (Weih, Van Newkirk, McCarty, & Taylor, 2000) and healthcare planners have got to prepare for the increasing burden of visual disability and blindness. To socioeconomic costs, Cruess et al. (2008) stated that the estimated annual societal costs of ‘bilateral’ AMD patients among Canada, France, Germany, Spain and the UK (calculated in euro in year 2005 values) ranged from 268 to 1311 millions, and that of ‘all’ AMD patients among these countries ranged from 671 to 3278 millions, which were substantial.

In Hong Kong, there are about 3,000 new cases of wet AMD (a type of AMD which causes irreversible vision loss) each year (Information Services Department [ISD], March 10, 2010). There is no such data as socioeconomic costs for AMD in Hong Kong has been collected officially. Rather, a population based survey
(Michon, Lau, Chan, & Ellwein, 2002) conducted in Shatin was comparable to Hong Kong with respect to population age and household income. According to the principal causes of presenting impairment and blindness, the study revealed that 4.7% of the visually impaired, 18.4% of the unilateral blindness and 27.1% of the bilateral blindness were caused by AMD (Michon, Lau, Chan, & Ellwein, 2002). These data followed immediately after those of two other ‘correctable’ causes as refractive error and cataract (Michon et al., 2002). In the context to ameliorate the self-care ability for those already diagnosed with AMD, educational interventions for older adults with AMD to mediate negative impacts of vision impairment or vision loss on their quality of life have become a research interest with evidence supporting their effectiveness.

The purpose of this dissertation is to translate the best evidence to practice for improving the care of older adults with AMD in the Elderly Health Centres in Hong Kong. Chapter 1 will describe the background knowledge of AMD, the need and significance of innovative interventions for caring older adults with AMD, and the aim and objectives of this translational project. Chapter 2 is the review of evidence. There will give the tables of evidence and will explain the methodology and results in the searches and quality appraisal, followed by data summary and synthesis. Chapter 3 will discuss the translation and application of the research
findings with the formulation of guideline recommendations for the SEP. Chapter 4 is the implementation plan. There will explain details regarding the communication plan and a brief description on a pilot study plan. Chapter 5 will account for the evaluation plan for the effectiveness and adoption of the SEP.

**Background**

**What is Age-related Macular Degeneration (AMD)?**

Age-related macular degeneration (AMD) is an eye disease caused by degeneration of retina due to old age. The disease specifically affects the macula of older adults. Macula is the central region of the retina which is responsible for clear and sharp central vision, such as reading labels, watching traffic lights and recognizing faces, etc. There are dry and wet forms of the disease. (OVSD, 2001). Patients with dry AMD have degeneration and atrophy of the macula of the eye and most are asymptomatic. However, dry AMD can transform into the wet type, which is the major cause of blindness in AMD. As in wet AMD, patients’ eyes develop abnormal blood vessels in-growing from the choroids (choroidal neovascularization). These vessels leak and bleed easily. When leaving it unattended, the blood and the exudation accumulated over the macular region
damages the photoreceptor cells over there and eventually causes visual loss which is not recoverable (OVSD, 2001). The patient will experience blurring of central vision, distortion of objects, straight lines appearing wavy and a central blind spot (scotoma) (OVSD, 2001). This greatly impairs quality of life. Age is a major risk factor strongly linked to AMD (OVSD, 2001). Other modifiable risk factors may include cigarette smoking, genetic tendencies, arterial hypertension, excessive sunlight exposure and non-balanced diets (International Council of Ophthalmology [ICO], 2011; OVSD, 2001).

Treatments of AMD

Neither operations (laser photocoagulation, macular surgery and photodynamic therapy) nor medications can reverse the impaired vision or degenerative condition. These treatments are ‘palliative’ because they serve only to retard the disease progress (ICO, 2011; OVSD, 2001). Moreover, to the operations, most patients are simply not candidates for such treatments either because the macular lesion is too centrally located or the risk of the surgery is too big (OVSD, 2001). To the medications, drugs for wet AMD are still on trial only (ISD, March 10, 2010).

Preventive Measures of AMD

There is no prevention of AMD (ICO, 2011). Controlling those modifiable
risk factors may help delay its onset or retard the progress of the irreversible disease.

**Affirming the Need and Significance**

**Consequence of AMD and Resource Implication**

Cruess et al. (2008) informed readers in the multi-countries study that AMD patients reported substantial health-related problems associated with health resource utilization. Among the sample studied, 12-22% of the patients fell in the previous 12 months in which half of them required medical treatments; 21-59% of the patients required prescription of vision-enhancing equipments, and 19-41% of the 54-81% patients living with a spouse or family member reported receiving assistance for activities of daily living (Cruess et al., 2008). In Hong Kong, the government has no formal statistics on AMD. For supplementary information, my 8-year experience in the Elderly Health Service (EHS) in Hong Kong found that AMD of different severities was affecting roughly 20% of the patients in our daily encounter who might or might not have an eye follow-up. Among the eighteen Elderly Health Centres (EHCs) in Hong Kong, the daily regular patient visits ranged from 30 to 40 cases. The disease leads to functional disabilities in
performing daily living activities, emotional distress (Rovner & Ganguli, 1998) and loss of self-worth (Hassell, Lamoureux, & Keeffe, 2006). A study (Au Eong, 2006) found that poor vision in elders was associated with falls, hip fractures, family stress, and depression. Study data showed that even moderate visual impairment (a visual acuity worse than 6/12) significantly decreased the enjoyment of healthy ageing (Ivers, Cumming, Mitchell, & Attebo, 1998.). In local situation, financial reason could be a factor preventing some elders from long-term drug treatment for AMD. The reason is that drugs for wet AMD are still on trial and are not standard drugs in the Hospital Authority (HA) Drug Formulary. Thus, HA patients who opt for the drug treatment currently need to purchase them from HA at their own expense (ISD, March 10, 2010). Together with the limited choice of treatment as discussed earlier, it is expected that the quality of life of elders with AMD declines with disease prognosis. Hence, AMD leads to human cost and has resource implication.

Current Educational Practice for Elderly with AMD

Hong Kong situation. In HK, there is currently no specifically designed educational programs for elders with AMD. For the Elderly Health Centres, they have been popular primary care providers among the local elderly population since the Government established the Elderly Health Service in 1998. EHCs
provide clinic service of health assessment, physical check up, counseling, curative treatment and health education to elderly. Elderly aged 65 and above can enroll as members of EHCs. A considerable number of members developed with AMD are therefore in regular contacts with EHCs. However, the current practice for AMD clients in the EHCs includes only general and brief health advice given by nurses which is not specific to AMD and is lack of scientific evidence support. Hence in the EHCs, an evidence-based innovative education programme is expected in managing the chronic condition.

**Review on educational programmes for AMD.** A study (Brody, et al., 2002) found that self-management was effective in improving health outcomes for older persons who have a variety of incurable chronic conditions, including asthma and arthritis, and for adults of varying ages in managing chronic diseases, like diabetes, heart diseases and cancer. A systematic review by Lee et al. (2008) concludes that self-management was a common element in AMD education programmes and there were research showing certain self-management programs were effective in reducing the disability due to AMD and avoiding depression associated with AMD.

**Research Question, Aim, and Objectives**
With the affirmed need and the significance of innovative programmes, there comes the research question, aim, and objectives of this translational study for subsequent literature search.

**Research Question**

Could a self-management education programme result in better improvement in emotional distress for older adults with age-related macular degeneration (AMD) than usual care?

**Aim**

To translate the best evidence of the innovative self-management education programme (SEP) to clinical practice guidelines for the Elderly Health Centres (EHCs) in Hong Kong

**Objectives**

The objectives of this dissertation are (1) to conduct a quality assessment of the reviewed literatures in AMD treatment/intervention; (2) to gather empirical evidence on the effectiveness of SEP in providing better health outcomes for older adults with AMD; (3) to determine the implementation potential of SEP for older adults with AMD in the EHC in Hong Kong; (4) to develop an evidence-based clinical guideline of SEP, and (5) to develop an implementation and evaluation
plan of SEP.
Chapter 2: Review of Evidence

Methodology

Search Strategies

**Inclusion criteria.** To identify eligible studies for analysis, the following presented the inclusion criteria.

*Study population.* The study population should be older adults aged 65 years or older who were experiencing vision loss / impairment due to AMD. There was no restriction on the years of AMD diagnosis.

*Intervention.* The intervention should be health education programmes including elements of self-management as an innovation. Self-management elements should include both problem-solving skills and the intention to increase self-efficacy such as in behavioral skills trainings. The intervention groups should be compared with controls receiving no education regarding AMD-related self-management elements. There were no restriction on the length and frequency of the programs and the disciplines of personnel conducting the interventions.
**Outcomes of interest.** Health outcomes such as self-efficacy, emotional status and functional ability

**Publication type.** Primary studies in randomized controlled trials

**Exclusion criteria.** The selection should exclude studies involving hospital in-patients and institutionalized elders (such as those who were living in residential care homes). Also, the selection excluded studies involving vision impairment or blindness which is attributed to other eye diseases rather than principally caused by AMD.

**Choice of electronic databases.** Ovid MEDLINE(R) (from 1948), CINAHL Plus (from 1937) and EMBASE (from 1947) were the databases used in electronic search.

**Use of key words.** Depending on the functions of individual databases, the searching used ‘Medical Subject headings’, ‘keywords’, ‘explode’, also ‘AND’ and ‘OR’ to combine and exclude papers. The keywords used are as follows: (for the clinical problem) macular degeneration, macular dystrophy, maculopathy, retinal degeneration; (for interventions) patient education, program, intervention, non-pharmacological, non-drug, teaching, skill training; (for outcomes) emotional status, activities of daily living, functional ability, self-efficacy, behavioral change, knowledge, health, attitudes, practice, and (for
the type of studies) randomized controlled trials, randomized controlled trial, randomized controlled trial.

Limits on searches. The search restricted publications to ‘10 years’ and to ‘English’ papers with ‘full text’. Also, searches included only published articles. Moreover, since randomized controlled trials are the most rigorous way of determining intervention effectiveness (Sibbald & Roland, 1998), which favor the development of evidence-based clinical guidelines, primary studies in ‘randomized controlled trials’ were the only publication type in the searches regarding the translation purpose in this dissertation paper. The searches applied other limits including ‘human trials’, ‘population aged 65 or above’, ‘therapy with best balance in sensitivity and specificity’, whichever applicable to the databases.

Manual screening. The selection process finally included manual screening for the electronically retrieved studies for their eligibility, by applying the criteria for inclusion of studies to the titles and located abstracts first, and then to the full-texts.

Reference lists of studies. The search included reference lists of all the relevant studies retrieved, with a prior screening of the list according to the study selection criteria specified earlier.

Data extraction. The tables of evidence (Appendix A) extracted and
recorded data of the eligible studies.

**Appraisal Strategies**

The Critical Appraisal Skills Programme (CASP) appraisal tool (Public Health Resources Unit, National Health Service, 2010) was the tool used to critically appraise and assess the methodological quality of the eligible studies following the full-text selection stage. The tool for randomized controlled trials was the only one used in this translational research because of the type of studies specified in the inclusion criteria earlier. Appendix B shows details of the checklist questions. Furthermore, the rating schemes provided in the “SIGN 50: A guideline developer’s handbook Annex B” (Scottish Intercollegiate Guidelines Network, 2011) (Appendix C) was the tool used to rate the level of evidence for each study.

**Results**

**Results from Searches**

The electronic databases located (after accounting for duplicates among searches within the individual database) 187 articles from Ovid MEDLINE(R), 2
articles from CINHAL Plus and 128 articles from EMBASE. Through title and abstract screening, 21 studies (12 studies from Ovid MEDLINE(R), 2 studies from CINAHL Plus and 7 studies from EMBASE) met the study selection criteria. After reviewing the full texts of those remaining 21 studies, 13 studies (7 studies from Ovid MEDLINE(R), 1 study from CINAHL Plus and 5 studies from EMBASE) satisfied the selection criteria. By excluding duplicated studies among the databases, there turned out to be 8 studies available. Together with one full-text-relevant study retrieved from a reference list of one of the identified studies, a total of 9 studies in RCT study design became eligible for inclusion (Brody et al., 2002; Brody, Roch-Levecq, Thomas, Kaplan, & Brown, 2005; Brody, Roch-Levecq, Kaplan, Moutier, & Brown, 2006; Dahlin, Sonn, & Svensson, 2002; Eklund, Sonn, & Dahlin-Ivanoff, 2004; Eklund, Sonn, Nystedt, & Dahlin-Ivanoff, 2005; Eklund, Sjöstrand, & Dahlin-Ivanoff, 2008; Rovner, Casten, Hegel, Leiby, & Tasman, 2007; Stelmack et al., 2008). Appendix D presented the history of the electronic searches. These nine eligible studies were publications between year 2002 to year 2008, with five conducted in U.S.A. and four in Sweden. To the studies excluded from the key word search results, the predominant were trials on drug therapies and nutritional supplements, while others were studies involving inpatients, subjects with another eye disease secondary to AMD, or the
comparison of an intervention with a control which, however, contained self-management elements. Table 1 presented the result from the searching and screening process.

**Table of evidence.** Appendix A presented the tables of evidence consisting the study designs, subject characteristics, sample size, intervention, controls, outcomes measures, time of follow-up and effect size.

**Results from Assessment and Appraisal**

**Overview of study characteristics.** First, the nine eligible studies reported on four intervention protocols and the other five were follow-up studies (Brody et al., 2005; Brody et al., 2006; Eklund et al., 2004, Eklund et al., 2005; Eklund et al., 2008). In other words, the studies by Brody et al. (2005) and Brody et al. (2006) reported findings of the medium-term follow-ups of the study by Brody et al. (2002) which reported short-term findings, while Brody et al., (2006) report the trial on a subgroup (depressed subjects) of the samples of Brody et al. (2002) but in a different perspectives. Similarly, the study by Eklund et al., 2004 reported long-term follow-up findings of the study by Dahlin et al. (2002). To the studies by Eklund et al. (2005) and Eklund et al. (2008), they reported findings of the long-term follow-ups of the study by Eklund et al., (2004). The study by
Eklund et al. (2005) differed in reporting cost-effectiveness of the study by Eklund et al. (2004) but provided additional summative data in the result and was therefore included, while Eklund et al. (2008) reported different outcome measures. Nevertheless, all nine interventions included elements of self-management for patients with AMD-related vision loss / impairment. Second, the effectiveness of the interventions was compared with that of the controls offering no self-management components. The controls used were the usual care group (Rovner et al., 2007), waiting-list groups (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008), tape-recorded lectures (Brody et al., 2005; Brody et al., 2006) and individual interventions (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008). Third, all the interventions took the form of a group programme, except the one by Rovner et al., (2007) which was an in-home individual programme. Fourth, participants in the interventions were community-dwelling elders, who were recruited from an university ophthalmology clinic in U.S.A. (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006), two low vision clinics in Sweden (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008), a retino-vitreous clinics in U.S.A. (Rovner et al., 2007) and two veteran affairs outpatient facilities in U.S.A. (Stelmack et al. 2008). Last but not least, all nine studies reported no adverse
Overview on methodological qualities. As a result from the appraisal using the CASP appraisal tool for RCTs (Public Health Resources Unit, National Health Service, 2010), the methodological qualities of the nine reviewed studies were either strong (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) or very strong (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Rovner et al., 2007; Stelmack et al., 2008), rated with a level of evidence as 1+ with a low risk of bias (those methodologically strong) or 1++ with a very low risk of bias (those methodologically very strong) respectively according to the rating schemes of SIGN (Appendix C). Appendix E summarized the results of the quality appraisal. Hence, it was convincing that findings from the review of these eligible studies were of reliable and crucial reference values in providing the framework for developing an evidence-based guideline of a health programme (or a Self-management Education Programme (SEP)) for AMD patients in the proposed clinical setting.

Internal validity of studies. The following accounted for the internal validity of the reviewed studies.

Research question. All nine studies stated clearly-focused questions in terms of population, intervention, control and outcomes, as what have been
described previously in the study selection criteria. All belonged to randomized controlled trial (RCT), which is a correct research approach for the question being asked.

**Randomization process.** All the nine reviewed studies reported the randomization process. Three studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008) reported the use of computer-generated randomization schedule and five (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Rovner et al., 2007) reported the use of a random-number table. Even, one study (Stelmack et al., 2008) accounted for stratification in randomization. Also, all studies reported no significant difference in baseline characteristics between treatment and control groups which showed that the randomization worked well.

**Blinding condition.** Studies in Brody et al. (2002), Brody et al. (2005) and Brody et al., (2006) shared the same protocol. The researchers mentioned the use of sealed envelopes, and that the assessors were blind to treatment allocation and were naïve as to the study hypotheses. Besides, the researchers describe details in avoiding the disclosure of group assignments. Rovner et al. (2007) mentioned the use of sealed envelopes. Stelmack et al. (2008) described that interviewers (assessors) administering questionnaires over telephone have been
masked to treatment assignment. The researchers instructed the patients not to disclose the group assignment and that there were ways to track the disclosures. Ultimately, there reported no disclosure. The four other studies (Dahlin et al., 2002; Ekund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) reported no blinding of assessors whom, however, did not involve in the programs and that the outcomes were self-reported which was unlikely to lead to observer bias.

*Treatments and follow-up analysis.* First, all the nine studies reported same follow-up schedules among treatment and control groups and there was no mention of additional treatments, which suggested that the studies treated all groups equally aside from the intervention. Second, all but one (Stelmack et al., 2008) of the nine studies did not report intention-to-treat approach, including the study by Eklund et al. (2004) and its follow-up studies (Eklund et al., 2005; Eklund et al., 2008) which reported using ‘modified’ intention-to-treat approach but actually the results failed to show that intention-to-treat analysis was employed. Consequently, these eight studies (Dahlin et al., 2002; Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Rovner et al., 2007) got certain subjects excluded from the analyses and so the samples might be no longer representative of the entire groups of interest. This type of analysis could be biased toward finding positive.
Nevertheless, the researchers report no significant difference in baseline characteristics between those completed the follow-ups and those who declined. Among them, three studies resulted with calculated dropout rates of smaller than 20%, which were 8.3% (Brody et al., 2002), 15.1% (Brody et al., 2005), 5.8% (short-term follow-up) and 7.8% (medium-term follow-up) (Rovner et al., 2007), and were acceptable. The five other studies got dropout rates of larger than 20%, which were 41.8% (Brody et al., 2006), 26.1% (Dahlin et al., 2002) and 42.8% in the studies by Eklund et al. (Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008), and were at risk of Type I error. Last, Stelmack et al. (2008) reported findings from intention-to-treat approach. The dropout rate was 7.1%. All studies stated reasons for the dropouts, including death, health problems, lack of time, loss of interest, travelling problem, memory problem and not traceable subjects.

**Power calculation.** Four out of the nine studies reported prior power calculation (Brody et al., 2002; Brody et al., 2005; Rovner et al., 2007; Stelmack et al., 2008), in which three studies (Brody et al., 2002; Brody et al., 2005; Rovner et al., 2007) estimated a power of 0.8 and the other (Stelmack et al., 2008) estimated a power of 0.9. Among these four studies, three (Brody et al., 2002; Brody et al., 2005; Stelmack et al., 2008) turned up with sufficient samples as calculated and attained the actual power as reported, while the other one (Rovner
et al., 2007) reported insufficient statistical power, committing the type II error. To the five other studies not providing statistical information about the power (Dahlin et al., 2002; Brody et al., 2006; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008), readers are unclear whether the sample numbers recruited have been sufficient to achieve the statistical conclusion validity. To add, although Brody et al. (2006) was a follow-up study of Brody et al. (2002), the former admitted insufficient sample size because the study worked on the depressed subgroup of the samples from Brody et al. (2002).

**Presentation and precision of results.** Differences in means, change in relative position, odds ratios and relative ratios were the various outcomes presented. All nine studies reported either 95% confidence interval (CI) or a significant level at p=0.05. All but one (Brody et al., 2006) studies stated upper and lower CI limits for the findings.

**Applicability of findings.** There have been consistent significant findings of the proposed innovation, which were associated with strong methodology studies among community elders who were experiencing vision loss / impairment due to AMD. Given the similar characteristics of target population and context, it will be a potential intervention that could be applied in the proposed clinical setting.
Summary and Synthesis

Data Summary

The following summarized data from the nine studies. The summary involved three aspects: (a) outcome examination, (b) the programme and (c) characteristics of participants.

Outcome examination. The following gave a summary on the outcomes of interest, time of outcome measurements, instruments in measurements and the effect size.

Outcomes of interest.

Primary and secondary outcomes. The six primary outcomes examined included ‘emotional distress’ (Brody et al., 2002; Brody et al., 2005), ‘perceived security in performing daily activities’ (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005), ‘depression symptoms’ (Brody et al., 2006), ‘incidence of clinical depression’ (Rovner et al., 2007), ‘vision-dependent function’ (Eklund et al., 2008) and ‘vision reading ability’ (Stelmack et al., 2008). There were seven secondary outcomes, which were ‘self-efficacy’ (Brody et al.,
2002; Brody et al., 2005; Brody et al., 2006), ‘incidence of clinical depression’ (Brody et al., 2005), ‘rate of relinquishing valued activities’ (Rovner et al., 2007), ‘general health’ (Eklund et al., 2008), ‘self-reported health problems’ (Eklund et al., 2008), ‘vision-dependent functions’ (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) and ‘other visual ability domains’ (Stelmack et al., 2008), including mobility, visual information processing, visual motor skills and overall visual ability.

Report rates on significant results. The following summarized for each of the outcomes the rate of significant results reported among all the trials attempting measurement of that single outcome. For primary outcomes, ‘emotional distress’ was significant in both of the two attempting studies (100% reported significant), ‘perceived security in performing daily activities’ in all of the three studies (100%), ‘depression symptoms’ in the one study (100%), ‘incidence of clinical depression’ in half of its reports within the same study (50%), ‘vision-dependent function’ in not even the only one study (0%), and ‘vision reading ability’ in the one study (100%). Similarly, for secondary outcomes, ‘self-efficacy’ was significant in all of the three attempting studies (100% reported significant), ‘incidence of clinical depression’ in the one study (100%), ‘rate of relinquishing valued activities’ in the one study (100%), ‘general
health’ in not even the only one study (0%), ‘self-reported health problems’ in the one study (100%), ‘vision-dependent functions’ in two of the three studies (66.7%), and ‘other visual ability domains’ in the one study (100%).

Significant results and levels of evidence. To those significant results, the following summarized the levels of evidence of corresponding studies. For ‘emotional distress’, ‘perceived security in performing daily activities’, ‘depression symptoms’, ‘incidence of clinical depression’ and ‘vision reading ability’ (i.e. 5 out of 6 primary outcomes), those significant results were associated respectively with two 1++ studies (Brody et al., 2002; Brody et al., 2005), three 1+ studies (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005), one 1++ study (Brody et al., 2006), one 1++ study (Rovner et al., 2007), and one 1++ study (Stelmack et al., 2008). For ‘self-efficacy’, ‘incidence of clinical depression’, ‘rate of relinquishing valued activities’, ‘self-reported health problems’, ‘vision-dependent functions’ and the ‘other visual ability domains’ (i.e. 6 out of 7 secondary outcomes), those significant results were associated respectively with three 1++ studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006), one 1++ study (Brody et al., 2005), one 1++ study (Rovner et al., 2007), one 1+ study (Eklund et al., 2008), two 1++ studies (Brody et al., 2002; Brody et al., 2005), and one 1++ study (Stelmack et al., 2008).
Non-significant results and levels of evidence. To those non-significant results, the following summarized the levels of evidence of corresponding studies. For ‘incidence of clinical depression’ (i.e. the primary outcome to which the rate of significant result calculated equaled 50%), the result non-significance was associated with a 1++ study (Rovner et al., 2007). For ‘vision-dependent function’ (i.e. the primary outcome to which the rate of significant result calculated equaled 0%), the result non-significance was associated with a 1+ study (Eklund et al., 2008). For ‘general health’ and ‘vision-dependent functions’ (i.e. the secondary outcomes to which the rates of significant results calculated equaled 0% and 66.7%), those result non-significances were associated with a 1+ study (Eklund et al., 2008) and a 1++ study (Brody et al., 2006) respectively.

Time of outcome measurements. There were generally three types of outcome effects among the nine studies: short-term (sustained within weeks to less than six months), medium-term (sustained up to the 6th month) and long-term (sustained over one year) effect. All studies examined the outcomes in follow-ups after completion of the interventions. Examination of the primary outcomes were as follows: ‘emotional distress’ at the 6th week (Brody et al., 2002) and 6th month (Brody et al., 2005); ‘perceived security in performing daily activities’ at the 4th
month (Dahlin et al., 2002) and 28th month (Eklund et al., 2004; Eklund et al., 2005); ‘depression symptoms’ at the 6th month; ‘incidence of clinical depression’ at the 2nd and 6th months (Rovner et al. 2007); ‘vision-dependent function’ at the 28th month (Eklund et al., 2008), and ‘vision reading ability’ at the 4th month (Stelmack et al., 2008). Examination of the secondary outcomes were as follows: ‘self-efficacy’ at the 6th week (Brody et al., 2002) and 6th month (Brody et al., 2005; Brody et al., 2006); ‘incidence of clinical depression’ at the 6th month (Brody et al., 2005); ‘rate of relinquishing valued activities’ at the 2nd and 6th months (Rovner et al., 2007); ‘general health’ at the 28th month (Eklund et al., 2008); ‘self-reported health problems’ at the 28th month (Eklund et al., 2008); ‘vision-dependent functions’ at the 6th week (Brody et al., 2002) and 6th month (Brody et al., 2005; Brody et al., 2006), and the ‘other visual ability domains’ at the 4th month (Stelmack et al., 2008).

**Instruments in measurements.** Means of outcome measurements were as follows: ‘emotional distress’ by the Profile of Mood States (POMS) (Brody et al., 2002) and the Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, research version (SCID) (Brody et al., 2005); ‘perceived security in performing daily activities’ by a self-designed test as devised in the study of Dahlin et al. (2002) (Eklund et al.,
‘depression symptoms’ by the Geriatric Depression Scale (GDS-15) (Brody et al., 2006); ‘incidence of clinical depression’ by the Hamilton Depression Rating Scale (HDRS) (Rovner et al., 2007) and SCID (Brody et al., 2005); ‘vision-dependent function’ by the National Eye Institute Visual Function Questionnaire (NEI-VFQ) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) and a test (but not traceable) (Eklund et al., 2008); ‘vision reading ability’ by the Veterans Affairs Low Vision Visual Functioning Questionnaire (VA LV VFQ–48) (Stelmack et al., 2008); ‘self-efficacy’ by the Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006); ‘rate of relinquishing valued activities’ by the NEI VFQ-17 (Rovner et al., 2007); ‘general health’ by the Short Form Health Survey (SF-36) (Eklund et al., 2008); ‘self-reported health problems’ by another test (but not traceable) (Eklund et al., 2008), and ‘other visual ability domains’ by the VA LV VFQ–48 (Stelmack et al., 2008).

Effect size.

Primary outcomes (significant treatment effect). For ‘emotional distress’, a negative pre-post value in the POMS indicates an improvement in emotional distress. In short-term effect, evidence showed a significant reduction of 7.09 mean total scores (CI -15.39 to -1.21) in the treatment group and an
increase of 3.41 mean total scores (CI -2.39 to 9.21) in the control group (Brody et al., 2002); in medium-term effect, there was a significant reduction of 11.64 mean total scores (CI -17.28 to -6.01) and an increase of 0.14 mean total score in the control group (Brody et al., 2005). For ‘perceived security in performing daily activities’ in short-term effect, evidence showed significant changes in relative position (RP) across the evaluated tasks from 0.08 (lower CI range 0.02 to 0.30) to 0.46 (upper CI range 0.21 to 0.62) in the treatment group (increased security), and changes in RP from -0.16 (lower CI range -0.23 to 0.08) to 0.15 (upper CI range 0.03 to 0.22) in the control group (decreased or increased security) (Dahlin et al., 2002); in long-term effect, there were significant changes in RP from 0.15 (upper CI range 0.3 to 0.63) to 0.46 (lower CI range 0.01 to 0.29) in the treatment group (increased security), and changes in RP from -0.32 (lower CI range -0.46 to -0.27) to -0.14 (upper CI range -0.17 to -0.003) in the control group (decreased security) (Eklund et al., 2004). For ‘depression symptoms’, evidence showed significant reductions of 2.92 and 1.00 mean total scores (both with decreased symptoms) in the treatment group and the control group respectively in medium-term effect (Brody et al., 2006). For ‘incidence of clinical depression’, evidence showed a significant odds ratio of 0.39 (CI 0.17 to 0.92) in short-term effect (Rovner et al., 2007). For ‘vision reading ability’, there was a significant ES
of 2.51 (score 2.43 with CI 2.07 to 2.77) in short-term effect (Stelmack et al., 2008).

**Secondary outcomes (significant treatment effect).** For ‘self-efficacy’ in short-term effect, evidence showed significant increases of 5.34 (CI 2.73 to 7.95) and 1.12 mean total scores (CI 0.82 to 3.07) (both with increased efficacy) in the treatment group and the control group respectively (Brody et al., 2002); in medium-term effect, evidence showed significant increases of 7.54 (CI 4.49 to 10.59) and 1.90 mean total scores (CI 0.03 to 3.83) in the treatment group and the control group respectively (Brody et al., 2005); another medium-term effect showed significant increases of 17.31 and 3.95 mean total scores in the treatment group and the control group respectively for the depressed subjects (Brody et al., 2006). For ‘incidence of clinical depression’, evidence showed a significant relative ratio of 0.49 (CI 0.25 to 0.97) in medium-term effect (Brody et al., 2005). For ‘rate of relinquishing valued activities’, evidence showed a significant odds ratio of 0.48 (CI 0.25 to 0.96) in short-term effect (Rovner et al., 2007). For ‘general health’, a RP value of larger than 1 shows a higher level of general health attained. There were significant RPs as 0.17 (CI 0.04 to 0.3) and 0.34 (CI -0.002 to 0.34) (both with lowered level of general health) in the treatment and control groups respectively in long-term effect (Eklund et al., 2008).
For ‘self-reported health problems’, a negative value in RP shows fewer health problems reported. Evidence showed a significant RP as -0.15 (CI -0.29 to -0.01) in the treatment group (fewer health problems) and a non-significant RP as 0.07 (CI -0.05 to 0.18) in the control group (more health problems) in long-term effect (Eklund et al., 2008). For ‘vision-dependent functions’, a positive pre-post value in the NEI-VFQ shows an improvement for this outcome. In short-term effect, evidence showed significant increases of 1.02 (CI -0.44 to 2.48) and 0.07 mean total scores (CI-1.16 to 1.31) in the treatment and control groups respectively (Brody et al., 2002); in medium-effect, evidence showed significant increases of 2.64 (CI -0.69 to 4.67) and 0.01 mean total scores (CI-1.37 to 1.38) in the treatment and control groups respectively (Brody et al., 2005); another medium-term effect showed significant increases of 5.7 and 3.34 mean total cores in the treatment and control groups respectively for depressed subjects (Brody et al., 2006). For ‘other visual ability domains’ (Stelmack et al., 2008), evidences showed significant ESs of 1.14 (score 0.84 with CI 0.58 to 1.10), 2.03 (score 1.38 with CI 1.15 to 1.62), 1.82 (score 1.51 with CI 1.22 to 1.80) and 2.51 (score 1.63 with CI 1.40 to 1.86) respectively for ‘mobility’, ‘visual information processing’, ‘visual motor skills’ and ‘overall visual ability’ in short-term effect (Stelmack et al., 2008).
Those significant findings in medium or long-term effects for certain of the outcomes (‘emotional distress’, ‘self-efficacy’, ‘vision-dependent functions’ and ‘perceived security in performing daily activities’) suggested that the programme effects in short-term measurements were able to sustain, and even to result in better improvements as participants practice the learnt skills for a longer period of time, up to a few months of six (Brody et al., 200 and Brody et al., 2005) or long (Eklund et al., 2004 and Dahlin et al., 2002).

*Primary outcomes (non-significant treatment effect).* For ‘incidence of clinical depression’, there was a non-significant odds ratio of 0.65 (CI 0.33 to 1.39) in medium-term effect (Rovner et al., 2007). For ‘vision-dependent function’, a negative pre-post value in the test shows an improvement in vision dependency in ADL. There was a non-significant RP as 0.11 (CI -0.03 to 0.25) (increased dependency) and a significant RP as 0.34 (CI 0.24 to 0.46) (increased dependency) in the treatment group and the control group respectively in long-term effect (Eklund et al., 2008)

*Secondary outcomes (non-significant treatment effect).* For ‘rate of relinquishing valued activities’, there was a non-significant odds ratio of 0.53 (CI 0.28 to 1.01) in medium-term effect (Rovner et al., 2007).
The programme. The following gave a summary on the mode of the programmes, key components of the programmes, programme duration and personnel conducting the interventions.

Mode of the programmes. Eight studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Stelmack et al., 2008) reported results from group interventions. The group sizes were known in four studies (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) as four to six subjects and in three studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) as eight to ten subjects. One study (Rovner et al., 2007) conducted an in-home individual intervention.

Key components of the programmes. The studies reported the following key components: Didactic presentation or education on disease information in four studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008), problem-solving skills or strategies in use of remaining vision and low-vision devices in all nine studies, cognitive skills training in three studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006), behavioral skills training or environmental adaptations in all nine studies, modeling in four studies (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al.,
2005; Eklund et al., 2008), booklets in four studies (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008), and counseling in one study (Stelmack et al., 2008).

Additionally, the study of Stelmack et al. (2008) suggested that at least 10 hours (averaged mean (SD) 10.46 (2.06) hours per patient in the treatment group) of interventional therapy, including a home visit and assigned homework to encourage practice, was justified for patients with moderate and severe vision loss from macular diseases.

Programme duration. To group interventions offered for treatment groups, the study of Brody et al. (2002) and its follow-up studies (Brody et al., 2005; Brody et al., 2006) reported a 6-week programme in weekly 2-hour sessions. The study of Stelmack et al. (2008) also reported a 6-week programme but in five weekly 2-hour sessions plus one home visit. The study of Dahlin et al., (2002), Eklund et al. (2004) and its follow-up studies (Eklund et al., 2005; Eklund et al., 2008) reported a 8-week programme in weekly 2-hour sessions. To the individual intervention, the study of Rovner et al. (2007) reported six in-home sessions, each in 45 to 60 minutes, during eight weeks.

Personnel conducting the interventions. All studies reported that the SEPs were led by trained professionals, including a professional in public health
and behavioral medication (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006), an occupational therapist (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008), nurses and a counselor (Rovner et al., 2007) and an optometrist and a low-vision therapist (Stelmack et al., 2008).

**Characteristics of participants.** The following gave a summary on the age and gender of participants, education years and the visual acuity.

**Age and gender.** The mean age of the samples ranged across eight studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Rovner et al., 2007; Stelmack et al., 2008) from 79 to 81 years. One study reported a median age of 79 years (Dahlin et al., 2002). Male samples ranged from 30% to 33.8% cross most of the studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Rovner et al., 2007) , while one study population got 97.6% male with a sample from the US military veteran (Stelmack et al., 2008).

**Education years.** Two studies (Brody et al., 2005; Rovner et al., 2007) reported the mean years of receiving education as 13.76 years and 12.5 years respectively.
**Visual acuity.**  Visual acuities, presented as means of LogMAR values of the better-seeing eye, ranged across five studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Rovner et al., 2007; Stelmack et al., 2008) from 0.60 to 1.11. Four studies (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) reported a median decimal value of visual acuity of the better-seeing eye as 0.3.

**Data Synthesis**

The following utilized the above summarized data to synthesis data for the proposed Self-management Educational Programme (SEP). The synthesis accounted for three aspects: (a) outcome examination, (b) the programme and (c) characteristics of participants.

**Outcome examination.**  The following gave the synthesis on the outcomes of interest, time of outcome measurements, instruments and effect size.

**Outcomes of interest.**

*Categorization of the outcomes.*  Firstly, in trying to get an overview of the preference in the outcomes of interest among the reviewed studies, the following categorized the numerous outcomes as mental health, general
health and functional health aspects. Among the primary outcomes, four (‘emotional distress’, ‘perceived security in performing daily activities’, ‘depression symptoms’ and ‘incidence of clinical depression’) out of the six belonged to the mental health aspect (66.7%) while the rest (‘vision-dependent function’ and ‘vision reading ability’) belonged to the functional health aspect (33.3%). Among the secondary outcomes, two (‘self-efficacy’ and ‘incidence of clinical depression’) out of the seven belonged to the mental health aspect (28.6%), two (‘general health’ and ‘self-reported health problems’) out of the seven belonged to the general health aspect (28.6%), and the other three (‘vision-dependent functions’, ‘rate of relinquishing valued activities’ and the ‘other visual ability domains’ including mobility, visual information processing, visual motor skills and overall visual ability) out of the seven belonged to the functional health aspect (42.9%). Under this categorization, the following showed the synthesizing process for the outcomes appropriate for the SEP in the coming up clinical guideline.

A priori consideration for adoption. In this dissertation, an important consideration for adoption during the synthesis for the outcomes was, if available, a priori condition regarding ‘evidence of consistent findings among relevant trials of comparatively higher levels of evidence’. The synthesis process
below related the *report rates on significant results* and the *levels of evidence* which have been summarized earlier in the Data Summary paragraphs.

*Primary outcomes to synthesize.* First, to the *mental health* aspect, all four outcomes were significant among all of the attempting studies (100% reported significant, except for ‘incidence of clinical depression' with 50% of its reports was significant). Taking consistent findings into consideration, ‘emotional distress’ and ‘perceived security in performing daily activities’ were preferable, because the findings were consistent among two and three studies respectively, while ‘depression symptoms’ and ‘incidence of clinical depression’ were respectively reported by a single study only. Further, by considering together with the levels of evidence, however, only ‘emotional distress’ was preferable for adoption because its findings were associated with 1++ studies, while ‘perceived security in performing daily activities’ was associated with 1+ studies only.

Second, to the *functional health* aspect, the only one finding for ‘vision-dependent function’ was non-significant, while the one for ‘vision reading ability’ was significant. Although the outcomes came from a study of 1+ and 1++ respectively, no consistent findings could be available. Both of them are not preferable for adoption.

*Secondary outcomes to synthesize.* First, to the *mental health* aspect,
both two outcomes were significant among all of the attempting studies (100% reported significant). Although all the findings were associated with 1++ studies, only ‘self-efficacy’ was preferable for adoption because findings were consistent among three studies, while only a single study examined the ‘incidence of clinical depression’. Second, to the general health aspect, the only one finding for ‘general health’ was non-significant, while the one for ‘self-reported health problems’ was significant. Although the outcomes were associated with a study of 1+ respectively, no consistent findings could be available. Neither of them was preferable for adoption. Last, to the functional health aspect, two (‘other visual ability domains’ including mobility, visual information processing, visual motor skills and overall visual ability, and ‘rate of relinquishing valued activities’) of the three outcomes were significant in a single study with 1++ evidence level respectively. Since consistent findings were not available, they were not preferable for adoption. For the other outcome ‘vision-dependent functions’, both significant findings (66.7% report rate among trials) and the non-significant finding (33.3% report rate among trials) were associated with studies of the same methodologically strong quality rated with 1++ evidence levels. However, the non-significant finding was associated with only a single study (Brody et al., 2006) which was originally designed for the depressed subjects (refer Table of Evidence
3 of 9), while the significant findings were consistent for samples blended with depressed and non-depressed subjects in two studies (Brody et al., 2002; Brody et al., 2005). As a result, ‘vision-dependent functions’ was adopted as an outcome.

Hence, the coming up SEP could adopt ‘emotional distress’ as a primary outcome, ‘self-efficacy’ and ‘vision-dependent functions’ as secondary outcomes for measuring the programme effectiveness. All these chosen outcomes showed consistent findings among studies of 1++ evidence level. Differences in means were the means of expression for these outcomes.

**Time of outcome measurements.** Since significant findings of each of the three chosen outcomes above were of short-term (Brody et al., 2002) to medium-term effects (Brody et al., 2005; Brody et al., 2006) in measurement, short-term effects as at the 6th week follow-up measurement (Brody et al., 2002) could be the measurement time for the intervention outcomes in the SEP.

**Instruments.** Regarding measures associated with significant findings for shot-term programme effects of the chosen outcomes, the POMS (Brody et al., 2002), AMD-SEQ (Brody et al., 2002) and NEI-VFQ (Brody et al., 2002) respectively for ‘emotional distress’, ‘self-efficacy’ and ‘vision-dependent functions’ could be the preferable tools to measure the outcomes of the SEP. For visual acuity, since the measures used in the study of Brody et al. (2002), of 1++
level of evidence, matched the measures being used in the practice setting of the programme proposer, the SEP could adopt the Snellen chart for measuring the visual acuity.

**Effect size.** As bounded by the evidence, effectiveness of the coming SEP could mean reaching a bottom-line effect (short-term) of 7 units of reduction in mean total score for ‘emotional distress’ (Brody et al., 2002), 5 units of increase in mean total score for ‘self-efficacy’ (Brody et al., 2002) and 1.5 units of increase in mean total score for ‘vision-dependent functions’ (Brody et al., 2002).

**The programme.** The following gave the synthesis on the mode of the programmes, key components of the programmes, programme duration and personnel conducting the interventions.

**Mode of the Programme.** Since eight out of the nine studies were in group interventions, which were associated with the significant findings, the proposed Self-management Education Programme (SEP) for the elders with AMD would be run in groups, with four to ten subjects for each group (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008; Stelmack et al., 2008).

**Key components of the programme.** Problem-solving skills and
behavioral skills trainings were the shared key components among all nine studies. Hence, they were the key components common for the SEP. Since the study (1++ evidence level) by Brody et al. (2002) shared the same chosen outcomes, which were all significant, as the proposed SEP, its other components as education on disease information and cognitive skills training could also be desirable. Additionally, the SEP could include homework to encourage practice and a home visit, as taking the suggestion by Stelmack et al. (2008).

**Programme duration.** Among the studies in group interventions, four reported a 6-week programme and the other four reported a 8-week programme. Since a 6-week duration (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008) showed adequate in achieving significant outcomes of short-term (Brody et al., 2002) to medium-term (Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008) effects, the proposed SEP could adopt a programme of 6-week in length. Similarly, the SEP could be on a weekly basis in 2-hour sessions, as all the group interventions did.

**Personnel conducting the intervention.** Since there was no specific linkage between the qualification of the intervention personnel and intervention effectiveness, it would suggest that appropriate training be given to the intervention personnel.
**Characteristics of participants.** The following gave the synthesis on the age and gender of participants, education years and the visual acuity.

**Age and gender.** Since the study selection criteria specified the age of target participants, the SEP should recruit subjects of 65 years or above. The linkage between genders and programme effectiveness was weak and should not affect subject selection.

**Education level.** There was no demonstration showing the linkage between education levels and programme effectiveness across the studies and so this factor should subject to local population features when recruiting subjects for the SEP.

**Visual acuity.** Since ‘visual acuity of 20/60 or worse in the better eye and 20/100 or worse in the other eye with habitual correction (by current glasses)’ by Brody et al., (2002) was the best supported evidence compared with the others, and that the study shared all the same outcomes as chosen for the coming SEP and was methodologically strong, this inclusion criteria should be one of the inclusion criteria in the coming SEP.
Conclusion

The review has shown high level and methodologically strong evidences which support that the SEP was effective in improving health outcomes of the elderly patients with AMD. The data summary has brought together the information systematically and allowed the synthesis of meaningful data regarding the SEP. After all, developing a Self-management Education Programme (SEP) for elders experiencing vision loss / impairment due to AMD is necessary in the local setting to benefit target clients. The next chapter will discuss the translation and application of the clinical guidelines.
Chapter 3: Translation and Application

Previous studies have shown that Self-management Education Programmes (SEP) for elders experiencing vision loss due to age-related macular degeneration (AMD) is effective in improving health outcomes. As a result, the SEP is being proposed to Elderly Health Centre A and Elderly Health Centre B in Hong Kong. For the Elderly Health Centres to conduct the SEPs, this chapter will assess the implementation potential of the proposed programme and discuss the evidence-based practice guidelines.

Implementation Potential

The implementation potential will include the examination on the transferability of the findings, feasibility, and cost-benefit ratio of the SEP (Polit & Beck, 2008).

Transferability of the Findings

Comparability of target population and setting. The nine reviewed studies targeted at community-dwelling elders with AMD-related vision loss / impairment and took place in primary care settings. The innovation (SEP) is likely
to ‘fit’ in the proposed settings, Health Centre A and Health Centre B, because they are clinics which provide primary health care service, health checks and education to elders living in Hong Kong community. This means the educational approach (SEP) to the health needs (self-care deficits due to AMD) of the elders falls within the Service’s scope of operation in the elderly health centres. Moreover, target populations in the studies share similar characteristics with the members in the health centres, regarding the age and condition of AMD among the clients. Although to the years of education level of the clients in the studies were twelve years more than that of the elders in Hong Kong, the linkage between education level and programme effectiveness should not influence the transferability of SEPs in the proposed centres. First, nurses from Health Centres A and B have been sophisticated in providing health education according to health literacy of the elders and with minimum jargons. Second, Hong Kong government agencies and non-government organizations nowadays widely adopt self-help programmes for health education with no exception to the elderly. Even, members of the EHCs have been participating various support groups learning self-help skills and have demonstrated subsequent improvement in health outcomes. Last but not least, the SEPs will deliver adaptation skills about activities of daily living as well as hands-on skills including the use of low-vision devices from
user-friendly design. As a result, education level shall not limit the acquirement of all those skills in living. Finally, cultural differences shall not interfere the programme transferability because key components of the SEP aim at overcoming vision-dependent self-care deficit in daily living activities by addressing problem-solving strategies which are universal to human needs. Hence, target population and setting of the innovation is transferable to the EHCs.

**Philosophy of care.** The aim of the SEP is to mediate negative impacts and ameliorate the self-care ability of older adults who are under the constraints of AMD, improving patients’ self-efficacy and quality of life. Program content of the SEP involves inputs from allied health professionals such as occupational therapists (OT) and clinical psychologists (CPY) besides nursing. This concurs with the philosophy prevailing in the health centres of the Elderly Health Service. The Elderly Health Service endeavors in whole-person, client-centered and multi-disciplinary team approach, aiming to provide primary health care to the elderly, improve their self-care ability, encourage healthy living and strengthen family support so as to minimize illness and disability (Department of Health HKSAR Government, 2011). Therefore, the shared philosophy enhances implementation potential of the SEP in EHCs.
Proportion of target population to be reached by the SEP. Take Health Centre A as an example, the daily patient attendance is about 40. Thirty percent of the attending members get follow-up appointments in eye specialties and about twenty percent of them got AMD of different severities. This ends up with approximately 2.4 patients with AMD (40 x 30% x 20%) in daily encounters, or 624 AMD patients (2.4 patients x 52 weeks x 5 days) in the health centre every year. The SEP is proposing once quarterly in the EHC. Since previous studies suggested 10 AMD patients to be accommodated in a SEP group, the SEPs will benefit 40 AMD patients per centre each year. If all the eighteen EHCs deliver the programme, it can anticipate an annual total of 720 program beneficiaries. SEPs cater the need of AMD patients to whom individualized nursing care is presently inadequate in the EHCs. This figure accounts for the potential improvement in quality of life for the numerous AMD patients and is worth attempting when considering the programme transferability.

Time needed for implementation and evaluation for a SEP. Based on the evidence of the reviewed studies, the SEP will be a 6-week programme, containing six 2-hour sessions on a weekly basis, plus a post-intervention evaluation at the sixth week following the last session. Owing that participant recruitment will take four weeks in an elderly health centre, while data collection
and analysis will finish in the same week was the post-intervention evaluation, the
time frame in conducting a pilot study (from participant recruitment to the
completion of data analysis) will take about four months. This time frame is
reasonable for the current scheduling of health education activities in the Health
Centres A and B as it is similar to all other support groups being held in the
centres.

In order to project a clear time frame for the whole project consisting of
pilot and main studies, Figure 1 illustrated the full schedule. The time estimation
for the full schedule (from preparative work and trainings, the pilot study in
Centre A and main study in centres A and B, till report preparation and results
dissemination) is approximately 1.8 years (92 weeks). Figure 2 provided
information regarding the proposed programme protocol.

Feasibility

**Freedom to carry out the innovation.** Nursing is the main discipline in
initiating the conduction of education programmes in the Elderly Health Service
(EHS) and so gets the freedom to arrange and carry out the innovation and have
the freedom to terminate it if considered undesirable. After obtaining the
endorsement on the final version of the SEP programme production and the
training sessions completed, nurses in individual EHCs are confident to launch the programme as applicable to their clients. Besides, to programme production and intervention processes, roles of the nurses are well-defined in EHS. To this, registered nurses or nursing officers in the outreach teams take up the roles as project in-charge and participate as programme designers, program coordinators and programme writers and editors. Nurses in the EHCs usually participate as programme proposers, interventionists and executors.

**Support from nurses and administrators.** Health education is a core activity in the Elderly Health Service. The existing channel for proposing health education programmes is well established. There are periodical Service Meetings which allow discussion of new programmes topics to obtain support and consensus among administrators and frontline staff. Hence, the implementation of the SEP fits in the existing agenda in the Elderly Health Service. The SEP is not likely to interfere inordinately with current staff functions because the primary care setting used to identify clients in need of health education and there are support group schedules predefined for health education programmes to fit in. Moreover, administrators in the primary care setting would welcome the innovation since the organizational climate is conducive to innovative programmes as well as research utilization. One example is that all frontline units
of the Department have their designated quality assurance nurses (QA nurses) who are encouraged to initiate and help out quality assurance project at clinic levels with support from administrators. Also, there are internal circulations reporting evidence findings for relevant nursing practices in the Department and periodical circulation of newly published journal articles relevant to the various Services. Administrators also make use of possible channels like electronic mails to disseminate evidence findings relevant to frontline practice and would grant the staff official release to attend research meetings when deemed necessary. All these allow opportunities for utilization of research findings. However, to the time of training, it could be a barrier considered by administrators because this could mean drawing part of the manpower form frontline service. Yet, in the light that the SEP could benefit numerous elders with AMD, whose needs are currently not addressed by any of the educational programme launched by the Elderly Health Service, the proposer will advise to fit the training in the existing training occasions. The administrators will find no difficulties in arranging the training because there are occupational therapists and nurses who are qualified professionals to conduct the training sessions and that the courses would have successful application in CNE (continuous nursing education) points that would facilitate the administrators in meeting the guidance in providing in-service
training. Also, a sufficient amount of training hours relevant to nursing practice is one of the staff achievements counted for in the ‘Key Result Area’ for the periodic appraisal report of nursing staff. Hence, the innovation is very likely to gain the support from the nurses and administrators.

**Cooperation of non-nursing disciplines.** One barrier could be that the new innovation will need to seek consultation advice from non-nursing disciplines, for example environmental modification might need the advice from occupational therapists while inputs from clinical psychologists could help in cognitive skills training. Simultaneously, the OT and CPY would not be the main interventionists in delivering SEP sessions in all the eighteen districts because of their tight patient consultation schedules. Nevertheless, considering to invite comments from the allied health professions during the production of teaching materials and to invite the transfer of necessary skills from them to the nurses in training sessions would possibly overcome those programme content relevant to allied health inputs. Fortunately, the Elderly Health Service has appointed shared allied health staff amongst the eighteen districts. This should manage to secure the assistance of staff with necessary skills and knowledge.

**Availability of measuring tools.** It is necessary to evaluate the effectiveness of the innovation and the process by which the SEP become
incorporated into the Elderly Health Centres. For the effectiveness of the SEP, the commonest patient outcomes include ‘emotional distress’ and ‘self-efficacy’, as stated earlier. The best evidence suggested the instruments POMS and AMD-SEQ (Brody et al., 2002) respectively for the two outcomes and the Snellen chart (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) for visual acuity test.

The POMS (Profile of Mood States) is originally a 65-item self-reported inventory designed to identify and assess transient, fluctuating affective states. The POMS has been validated for use with a variety of healthy, physically ill and psychologically ill populations, including the older population. However, the time and means to complete the POMS in EHCs needs further consideration. First, the original 65-item assessment form may take up to 20 minutes for those physically ill to complete (Curran, Andrykowski, & Studts, 1995). However, since elders with AMD are under the influence by visual impairment or legal blindness and the aging process, they will spend more time to complete the POMS. Second, for similar reason, self-administration may not be suitable for finishing with the POMS. Thus, in view of the time constraints, another shortened version (POMS-SF) of the original POMS consisting 30-times instead, which reflects the need for a rapid, economical method of identifying and assessing transient, fluctuating affective states (Chen, Snyder, & Krichbaum, 2002), is preferable. The
correlations between the subscale and the total scores in POMS and POMS-SF are high, equal to or exceeding 0.84 (Curran et al., 1995). Also, to get rid of participants’ visual problems, nurse-administered method will be desirable for the POMS-SF in the SEP innovation. One advantage of that kind of administration is that the primary care nurses could rephrase the vocabulary meanings in the inventory if necessary to facilitate those elders with lower literacy. The translated Chinese version of POMS-SF is as reliable as the original English version and is appropriate for use with Chinese elders (Chen et al., 2002).

The AMD-SEQ (Macular Degeneration Self-Efficacy Questionnaire) is originally a 13-item scale which evaluates the degree of self-confidence and underlying expectations about an individual’s ability in accomplishing situations related to AMD. Previous studies adopted the AMD-SEQ (Brody et al., 2012; Brody et al., 2011; Brody et al., 2002; Brody et al., 2006; Brody et al., 2005; Brody et al., 1999), which has been shown reliable. The proposer attempted to locate the questionnaire on the web but failed even with the assistance from university librarians. Thus, an e-mail was sent to Professor Stuart I. Brown, M.D., who is in the author groups of three of the reviewed studies (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006). Dr. Brown is the Head of the Shiley Eye Center at the University of California at San Diego and his innovative research in
ophthalmology and patient care has dramatically improved the quality of life of countless individuals (University of California, San Diego, n.d.). Finally, Professor Barbara Brody, the owner of the AMD-SEQ, granted the adoption and reprinting of the questionnaire (Appendix F) in this dissertation body, through a reply mail from Dr. Monya Rilea, a specialist to Professor Brown. A Chinese translation followed by validation of the version will be performed.

**Cost-to-Benefit Assessment**

**Potential benefits from the implementation of innovation.** To client benefit, previous studies demonstrated that the Self-management Education Programme (SEP) improved favorable health outcomes, achieving better mood states of participants than usual care or other interventions not incorporated with AMD-related self-management elements (problem-solving skills and the intention to increase self-efficacy). The mean total scores in the measure of ‘emotional distress’ reduced 7 units after the SEP which was significantly (p=0.02) different from an increase of 3.41 units after the usual care and didactic intervention (Brody et al., 2002). These changes were also prominent for the depressed subjects (Brody et al., 2006). Moreover, the SEP even demonstrated better (p=0.008) medium-term effect (6 months) in improving emotional distress than the usual care and didactic intervention (Brody et al., 2005). Similarly, evidence showed
that the SEP achieved significantly better self-efficacy (p=0.02) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) and vision-dependent functions in daily activities (p=0.04) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006).

To the healthcare teams, the innovation is likely to empower the ability to care for patients with AMD, increase professional image and improve staff morale.

To the healthcare system, implementing the innovation means an active strategy in primary care against the deteriorating health status of patients with AMD, prevention of possible complications from visual disability and blindness, like subsequent falls, geriatric depression, home accidents and the demand for home care services, emergency care, hospital services, residential care services, community nursing service and welfare provision, which could be a substantial financial burden. With implementation of the SEP, considerable healthcare expenses, including chronic consultations by specialists and general practitioners and the prescription of assistive devices, following that progressive age-related disease will hopefully be reducing.

**Potential risk from the implementation of innovation.** Based on the study reports published by past literatures and the design of the innovation, as
well as to the primary care experience in the department and the involved staff, the SEP is not likely to cause potential adverse effects.

**Disadvantages of maintaining current practice.** There are economic consequences if the AMD problem is left unattended at the primary care level. Maintaining current practice could mean a loss to the service in improving health outcomes of AMD patients which could mean anticipated expenses in treatment and administration cost to health sectors, because of the possible complications from visual disability and blindness as mentioned previously. Simultaneously, reluctance in change will trade off the potential health benefits to the clients. Also, there is the cost of family members caring for the sick.

**Cost-benefit ratio (CBR).** A way of judging the worth of the SEP is by asking if dollar benefits exceed dollar costs. Hence, the cost-benefit ratio (CBR) calculated below includes an estimation of the potential costs and benefits of delivering the SEP.

**Potential costs of the SEP.** The potential costs comprise the *Non-recurrent (investment) Cost* and the *Recurrent (operating) Cost*. Both of them take into account personal emoluments.

*The Non-recurrent (investment) Cost* is mainly the production expenses to generate the SEP programme contents (including cost of time spent...
on meetings and piloting) and the subsequent cost of replicating resource copies (one copy to be owned by each centre) for the eighteen EHCs for their long-term use. Thus concerning the production process, the number of staff involved, staff rankings, emoluments, working hours and material costs are considered. Owing that the production of master education kits is predominantly the duty of work of outreach teams of the Elderly Health Service (EHS), the cost per working session (1 working day equals 2 working sessions) is to calculate first. Based on the holidays gazetted for year 2012, the cost per working session by a registered nurse (RN) will be $744 (annual salary $366,000 / (246 working days x 2 sessions per day)), that for a nursing officer (NO) will be $1,150 (annual salary $566,400 / 492 sessions), and that for an occupational therapist (OT) will be $715 (annual salary $351,600 / 492 sessions). To the number of working sessions spent on the production of the master kit, estimation made is that a RN uses 4 sessions per 5 working days and a NO uses 2 sessions per 5 working days. Consequently, during the 8-week preparation phase shown in Figure 1, the time spent on the master kit will be 32 sessions (8 weeks x 5 working days per week x 4/5 session) by a RN and 16 sessions (8 weeks x 5 working days per week x 2/5 session) by a NO. Estimated time cost spent by EHC nurses of the EHS will be equivalent to 3/4 working session in an outreach team. The anticipated involvement of an OT will
be 2 sessions and that of a graphic designer (GD) will be 3 working days. Adding together the cost for piloting the project by EHC staff (calculated as time cost by an outreach RN for nursing staff) and material costs, Table 2 showed the estimation on the Non-recurrent (investment) Cost.

The Recurrent (operating) Cost mainly covers the expenses in running the SEP. The cost estimation is based on running 4 SEPs per year in each of the eighteen EHCs in full scale implementation. Again, activities by nursing staff in the EHCs are calculated as time cost by an outreach RN. Table 3 showed the estimation on the Recurrent (operating) Cost per annum.

Since overhead costs such as capital costs already exist before the production of the SEP and the capital user is the property owner, the production and delivery of SEPs will not incur extra increase in such cost expenditures (or loss in incomes) and therefore neither the calculation for the investment (non-recurrent) nor the operating (recurrent) costs include the overhead costs. The above calculations also base on an assumption that expenses on lighting and air-conditioning are covered in the routine operation costs which do not alter with the different types of activities taking place within the premises.

With an estimation that health education programmes are revised on an average of five years in EHS, the below calculates the grand total for the potential
costs of the SEP in a year.

Potential costs of the SEP (grand total) in a year

\[
= \text{annual total Recurrent Costs (E) x 5 + total Non-recurrent Costs (D)}
\]

\[
5
\]

\[
= \text{HK\$ (430,100 x 5 + 158,300)}
\]

\[
5
\]

\[
= \text{HK\$ 461,760 (F)}
\]

**Potential benefits of the SEP.**  A major outcome benefit of the SEP to be observed in the coming guideline protocol will be the improvement in emotional distress (Brody et al., 2002; Brody et al., 2005). The study by Brody et al. (2005) of strong methodological design calculated the outcome difference in the incidence of depression between the intervention group and the group with no SEP treatment. Findings showed that the SEP prevented 10% of the non-depressed AMD participants from developing depression after the programme (Brody et al., 2005). The potential benefits of SEP estimated are therefore based on the prevention of geriatric depression (percentage incidence of geriatric depression avoided). When considering that the 720 SEP participants are
free from depression when they are recruited, the number of elders being prevented from depression at programme end per year would be 72 (720 participants x 10%). Hence, considering that each depressive elder attends minimally one visit to a general outpatient clinic of HA and one visit to a specialist outpatient clinic respectively for diagnosis and treatment in the year, the service cost for each patient will be $1,260. Thus, by delivering SEP in EHS, the potential cost saved from HA consultations in a year by preventing non-depressed AMD patients from depression will be $907,20. Similarly, cost saved from EHS service regarding the depressed patients and other health costs and social costs are calculated. Table 4 showed the estimation.

Hence, the estimated potential benefits of SEP (grand total) in a year

\[
= (G) + (H) + (I)
\]

\[
= \text{HK$}\ (90,720 + 14,400 + 5040,000)
\]

\[
= \text{HK$}\ 5,145,120 \ (J)
\]

Thus, The cost-benefit ratio (CBR)

\[
= \frac{\text{Potential costs (F)}}{\text{Potential benefits (J)}}
\]

\[
= \frac{\text{HK$}\ 461,760}{\text{HK$}\ 5,145,120}
\]

60
= 0.09 (to the nearest hundredth)

After all, the cost and benefits which have been accounted lead to the conclusion that benefit of implementing the SEP is likely to outweigh the cost.

The innovation is worth implementing in the Elderly Health Centre of EHS.

Evidence-based Practice Guidelines

Overview of the Guidelines

- Evidenced-based Clinical Guideline

  This SEP educational training programme incorporates with the concept of ‘self-management’ in the attempt to effectively improve health outcomes for older adults whose daily living is pessimistically affected by an incurable chronic disease, age-related macular degeneration. This guideline protocol also informs nursing staff of effective evidence-based practices in enhancing patient self care and gives nurses more autonomy in their professional practice.

- Guideline Title

  An Evidence-based Guideline on a Self-management Education Programme (SEP) for Older Adults with Age-related Macular Degeneration (AMD)

- Intended Users
Nurses in the Elderly Health Centres

- **Purpose of the Guidelines**

  To provide the primary care setting with recommendations based on the best evidence practice shown by reviewed literatures for conducting Self-management Education Programmes for older adults who are experiencing vision impairment or blindness due to age-related macular degeneration, in order to optimize functions and quality of life.

- **Objectives of the Guidelines**

  The objectives of the guidelines are (1) to update nursing practice for the care of older adults with AMD; (2) to improve health outcomes for older adults with AMD.

- **Target Group**

  Community-dwelling elders aged 65 years or older who are experiencing vision impairment or vision loss due to AMD.

  *Note: This guideline is not directed to those elders having vision impairment or blindness which is attributed to other ophthalmological diseases rather than principally caused by AMD. This is also not directed for patient with cognitive impairment or hearing problems which disable their respond in normal conversations.*
Methods

Assessing the quality and strength of the evidence. The appraisal tool from the Critical Appraisal Skills Programme (CASP) (PHRU, NHS, 2010) (Appendix B) was the instrument adopted to appraise and assess the methodological quality of the identified studies. The Rating Schemes of Scottish Intercollegiate Guidelines Network (SIGN, 2011) (Appendix C) was the according reference to rate the level of evidence.

Formulating the recommendations. The Rating Scheme of SIGN: Key to Grades of Recommendations (SIGN, 2011) (Appendix H) was the scheme used to grade the guideline recommendations.

Recommendations

The following are the formulated recommendations for the Self-management Education Programme (SEP).

Recommendation 1.0 Who should be recruited to the programme?

Community-dwelling older adults aged 65 years or above;

- Recruiting community-dwelling elders (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Rovner et al., 2007; Stelmack et al., 2008) (1++); (Dahlin et al., 2002; Eklund et al., 2004; Eklund et...
An age of 60 years or over was an inclusion criteria (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

An age of 65 years or over was an inclusion criteria (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+); (Rovner et al., 2007) (1++).

The mean age of participants was 82 years (Brody et al., 2006) (1++); 81 years (Brody et al., 2002; Brody et al., 2005; Rovner et al., 2007) (1++); 80 years (Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+); 79 (Stelmack et al., 2008) (1++), and the median age as 79 years (Dahlin et al., 2002) (1+).

By considering together with the minimum age to enroll as a member of an Elderly Health Centre, which is 65 years, the minimum age to be considered for the programme should then be at least 65 years.

**AMD is a principal cause for the visual problem;**

- No other unstable eye disease or vision loss due to other eye disease (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

- AMD as primary eye diagnosis (Dahlin et al., 2002; Eklund et al.,
2004; Eklund et al., 2005; Eklund et al., 2008) (1+); (Stelmack et al., 2008) (1++);

- AMD in one eye diagnosed within the preceding 6 months and preexisting AMD in the fellow eye (Rovner et al., 2007) (1++)

A visual acuity of 20/60 (or 0.5 in LogMAR values) or worse in the better eye and 20/100 (or 0.7 in LogMAR values) or worse in the other eye with habitual correction by current glasses

- A visual acuity in the better-seeing eye worse than 20/100 and better than 20/500 was in the inclusion criteria (Stelmack et al., 2008) (1++);

- Visual acuity of 20/60 or worse in the better eye and 20/100 or worse in the other eye with habitual correction with current glasses was in the inclusion criteria (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

- A distance visual acuity with best correction in the better eye of 0.1 or worse (i.e. 20/25 or worse) was in the inclusion criteria (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+).

- The mean value of visual acuity was 1.26 (Brody et al., 2006)
(1++); 1.11 (Brody et al., 2002; Brody et al., 2005; Stelmack et al.,
2008) (1++); 0.6 (Rovner et al., 2007) (1++), and the median value
was 0.3 (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al.,
2005; Eklund et al., 2008) (1+).

Since a visual acuity in an eye of 20/70 or better (with habitual
correction) is accepted normal under the current clinical practice protocol
of the EHC, the evidences from Brody et al (2002), Brody et al (2005) and
Brody et al. (2006) are comparatively the most suitable for adoption in this
guideline.

Recommendation 2.0  Who are qualified to conduct the programme?

Registered nurses trained in public health programmes or nurses who
are experienced in public health care practice are qualified to lead the
SEP.

- A professional in public health and behavioural medication (Brody
et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++); an
occupational therapist (Dahlin et al., 2002; Eklund et al., 2004;
Eklund et al., 2005; Eklund et al., 2008) (1+); nurses and a
counselor (Rovner et al., 2007) (1++), and an optometrist and a
low-vision therapist (Stelmack et al., 2008) (1++).

Among the variety of professional qualifications suggested from the above evidences, public health nurses and nurses experienced in primary care practice in the EHCs are used to devising lesson plans, leading and co-ordinating production of education programmes and leading patient support groups. Thus, the nurses will be the suitable personnel to be responsible to conduct SEPs in the EHCs.

**Recommendation 3.0  Key components of the programme**

The self-management programme should include three indispensable components: ‘problem-solving skills’ including problem identification and strategies planning; ‘behavioral skills’ including adaptations and modeling, and ‘cognitive skills’ training. (Figure 2)

- Problem-solving skills (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Rovner et al., 2007) (1++); (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

- Strategies in use of remaining vision and low-vision devices (Stelmack et al., 2008) (1++);

- Strategies to achieve valued functional goals (Rovner et al., 2007)
Cognitive skills training (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

Behavioral skills training (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Rovner et al., 2007) (1++); (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

Environmental adaptations (Stelmack et al., 2008) (1++);

Modeling (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

Counseling (Stelmack et al., 2008) (1++).

Recommendation 4.0  Mode of delivering the programme

The programme should run in groups;

- Group intervention (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006; Stelmack et al., 2008) (1++); (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

- In-home individual intervention (Rovner et al., 2007) (1++).

Each group should be in four to ten participants.

- In groups of four to six participants (Dahlin et al., 2002; Eklund et
al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

- In groups of eight to ten participants (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++).

**Recommendation 5.0  Duration and frequency of the programme**

A 6-week programme length in weekly 2-hour sessions plus a home visit should be appropriate.

- A 6-week programme in weekly 2-hour sessions (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

- A 6-week programme but in five weekly 2-hour sessions plus one home visit (Stelmack et al., 2008) (1++);

- A 8-week programme in weekly 2-hour sessions (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

- Additionally, Stelmack et al. (2008) suggested that at least 10 hours (averaged mean (SD) 10.46 (2.06) hours per client) of interventional therapy, including a home visit and assigned homework to encourage practice, was justified for patients with moderate and severe vision loss from macular diseases (1++).
Since evidences showed that a 6-week duration was adequate in achieving significant outcomes of short-term to medium-term effects, this guideline suggests a 6-week programme for the proposed SEP.

**Recommendation 6.0 Teaching and learning strategies**

The programme design for effective learning should incorporate didactic presentation; guided practice; hands-on demonstrations; discussions; self-reflection; case studies; skills training (learn by doing); self-directed learning, and home modification. (Figure 2)

- Professionals giving brief presentations and formal lectures; guiding participants through a hierarchy of behavioral challenges to improve problem-solving skills; cognitive components included hands-on demonstrations and discussions of available visual aids and services; re-evaluation of perceived barriers to independence; peers and group leaders providing positive challenges; behavioral skills training in communicating with others about visual disability, handling a variety of challenges, and requesting assistance; modeling adaptive behaviors for the participants (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);
The occupational therapist provided information and skills training based on the occupational categories and guided and encouraged the participants in the learning process; participants preparing themselves by reading relevant chapters and formulating questions before participating in the sessions (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+);

To practice learnt skills routinely to develop practical compensatory strategies to achieve valued functional goals (Rovner et al., 2007) (1++);

Teaching environmental adaptations and setting up low-vision devices through home visits (Stelmack et al., 2008) (1++).

**Recommendation 7.0  Required assignments**

**Five hours of homework per week to practice performing everyday tasks and using adaptive devices.**

Assigning five hours of homework per week to each participant to practice performing everyday tasks and using low-vision devices. Reviewing the homework with the patient during the next weekly therapy session (Stelmack et al., 2008) (1++).
Recommendation 8.0  Major clinical outcomes

The programme should include ‘emotional distress’ as a primary outcome and ‘self-efficacy’ as a secondary outcome.

Primary outcomes examined:

- emotional distress (100% reported significant) (Brody et al., 2002; Brody et al., 2005) (1++);
- perceived security in performing daily activities (100% reported significant) (Dahlin et al., 2002; Eklund et al., 2004; Eklund et al., 2005) (1+);
- depression symptoms (100% reported significant, consistent findings not shown) (Brody et al., 2006) (1++);
- incidence of clinical depression (50% reported significant, consistent findings not shown) (Rovner et al., 2007) (1++);
- vision-dependent function (none reported significant) (Eklund et al., 2008) (1+);
- vision reading ability (100% reported significant, consistent findings not shown) (Stelmack et al., 2008) (1++).

Secondary outcomes examined:
self-efficacy (100% reported significant) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

incidence of clinical depression (100% reported significant, consistent findings not shown) (Brody et al., 2005) (1++);

rate of relinquishing valued activities (100% reported significant, consistent findings not shown) (Rovner et al., 2007) (1++);

general health (none reported significant) (Eklund et al., 2008) (1+);

self-reported health problems (100% reported significant, consistent findings not shown) (Eklund et al., 2008) (1+);

vision-dependent functions (66.7% reported significant) (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++);

other visual ability domains (100% reported significant, consistent findings not shown) (Stelmack et al., 2008) (1++)

Outcomes showing evidence of consistent findings among trials of comparatively higher levels of evidence were therefore preferable for adoption as the major outcomes for the SEP.
Recommendation 9.0  When to evaluate the clinical outcomes

To evaluate the outcomes at the 6\textsuperscript{th} week follow-up to look for programme effects

\textit{Short-term measurement (sustained within weeks to less than six months)}:

- at the 6\textsuperscript{th} week follow-up (Brody et al., 2002) (1++);
- at the 4\textsuperscript{th} month follow-up (Dahlin et al., 2002) (1+);
- at the 2\textsuperscript{nd} month (Rovner et al., 2007) (1++);
- at the 4\textsuperscript{th} month follow-up (Stelmack et al., 2008) (1++).

\textit{Medium-term measurement (sustained up to the 6\textsuperscript{th} month)}:

- at the 6\textsuperscript{th} month follow-up (Brody et al., 2005; Brody et al., 2006) (1++);
- at the 6\textsuperscript{th} month follow-ups (Rovner et al., 2007) (1++).

\textit{Long-term measurement (sustained over one year)}:

- at the 28\textsuperscript{th} month follow-up (Eklund et al., 2004; Eklund et al., 2005; Eklund et al., 2008) (1+).

Evidences showed that only measurements at the 6\textsuperscript{th} week, 2\textsuperscript{nd} month and 28\textsuperscript{th} month follow-ups were associated with significant findings in both the primary and secondary outcomes, so the suggested follow-up
measurement for the SEP could be as soon as the 6th week after the last session.

**Recommendation 10.0  Tools for measuring the outcomes**

The shortened version of Profile of Mood States (POMS-SF) and Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ) should be the tools for measuring the major outcomes specified in Recommendation 8.0.

*Emotional distress*

- measured by POMS (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++).

*Self-efficacy*

- measured by AMD-SEQ (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006) (1++).

Since the shortened version (POMS-SF) of the original POMS is readily available and accessible and that the correlations between the subscale and the total scores in POMS and POMS-SF are high, this guideline suggests using the POMS-SF (Chen et al., 2002) instead of the full version for more efficient use of resource under time constraints as discussed for the feasibility of the innovation
previously. Also, nurses to administer the questionnaires is preferable to self-reporting due to elders’ vision problems, time constraints and literacy reasons.

Recommendation 11.0  Keeping loyalty

Making biweekly telephone calls during the follow-up period after completion of the programme may help keep participants engaged in the programme and gain their co-operation in completing the programme evaluation.

- Participants received bimonthly telephone calls during the 4-month follow-up period after the completion of intervention as to keep patients engaged in the study to prevent attrition and to report adverse events (Stelmack et al., 2008) (1++).

Recommendation 12.0  Sustaining programme effects

Arranging booster lesson(s) may help sustaining the programme effects for a longer period. At least one booster lesson at the 6th month after the last programme session could be considered.

- Findings from Rovner et al. (2007) suggested that booster treatments for problem-solving treatment (PST) subjects or rescue
treatments for those with low-level depressive symptoms might be necessary to sustain PST’s ability to prevent depressive disorders.

There were evidences from the reviewed literatures showing that effectiveness of the outcomes (emotional distress and self-efficacy) of SEPs sustained significant up to even the 6th month follow-up (Brody et al., 2002; Brody et al., 2005; Brody et al., 2006). Hence, arranging at least one booster lesson at the 6th month should be reasonable to sustain longer programme effects up to a year.

**Conclusion**

This chapter has concluded with the assessment of implementation potential that the SEP programme is worth trying in the Elderly Health Centres and has consequently formulated recommendations for the practice guidelines of SEP for use in the EHC. The next chapter will explain the implementation plan, which includes the communication plan and the pilot study plan.
Chapter 4: Implementation Plan

In this chapter, the implementation plan will address the communication plan and a pilot study plan. The communication plan will involve stakeholders identification followed by the communication process. The pilot study plan will briefly introduce the design, setting, subject recruitment, intervention and measurements of the outcomes.

Communication Plan

Well-planned communication which is effective to address concerns of the involved stakeholders is an important activity when implementing change.

Stakeholders Identification

The paragraphs below indentify six types of stakeholders, who could have direct influence over or could be affected by the implementation of the SEP, for the proposed clinical setting.

The first one is the Senior Nursing Officer (SNO) of the Elderly Health Service (EHS) of the Department. She is a key person to support the programme and to authorize the proposal of the new topic and lesson plan in the service
meetings which are held periodically in EHS. The SNO will concern the clinical effectiveness, transferability, feasibility and the anticipated cost of the SEP.

The second one is the administrators who participate the periodic service meeting. The group comprises Senior Medical Officer of the EHS, nursing officers from Elderly Health Centres (EHC) of different districts and allied health professionals including occupational therapists and clinical psychologists. These people are the key administrative group to endorse the SEP lesson plan and the programme contents. Their major concerns will be similar to that of the SNO, as well as the impact on frontline practice and workload.

The third is the frontline nurses in the elderly health centres. They are the main users of the proposed guideline. They will concern the workload, time cost, client benefit, influence on routines, ease of use of the guideline and the complexity of the innovation.

The fourth is the occupational therapists. They deliver home visits in the SEP and so are the users of the SEP guideline. They are also the trainers who are responsible to transfer the nurses with adaptive skills concerned by the AMD elders. Their major concerns will be the workload, client benefit and the time cost in training.

The fifth is the elders with AMD, who are the target clients of the
programme. Their main concern will be the benefits over their vision-related quality of life.

Last but not least are the QA nurses who are the frontline nurses coordinating projects related to quality assurance service at the clinic level. They will be enlisted to the working group of SEP. Major concerns of them will be similar to other frontline nurses, also an additional concern about the transferability and feasibility of the SEP.

**Communication Process**

**To initiate the change.** First, the proposer will begin by initiating an informal meeting in own clinic to share the innovation with other nursing colleagues, including the QA nurse, and the occupational therapist. The sharing will focus on the inadequate care in the current service for those elderly members having AMD and will highlight the evidence support from the previous literatures about the effectiveness of the Self-management Education Programme in improving health outcomes of the elders with AMD. Besides, the sharing will reinforce a message that the proposed innovation will cause limited influence on clinic routines and the workload, and will explain the brief content of the SEP programme. This initial step is important to gain and secure the support for promoting the change. After that, the proposer will engage the support and
cooperation of professionals by forming a working group for the SEP. The working group will include the proposer, one QA nurse, one occupational therapist, one nursing officer and one medical officer. The group will share within its members the clinical benefits, feasibility and transferability of the SEP and the proposed guideline. The working group is formed in order to take the role to initiate communication with the administrators, to guide and sustain the changing process, and to be responsible for the pilot study and the evaluation in the main study. To the communication with administrators, the working group will begin by approaching the SNO of EHS and to share with her the SEP proposal. The sharing will focus on the clinical effectiveness, transferability and feasibility. Also, the working group will present and explain to her the programme protocol, proposed time schedule and the resources and skills required. The group will prepare powerpoint presentation slides and word documents for the communication. After obtaining the authorization from the SNO, the working group will submit the new topic and a lesson plan to the Service Meeting for discussion. By that time, the working group will sit in the Service Meeting to introduce and share the innovation and to gain the endorsement of the project in the meeting. The group will prepare a fifteen-minute powerpoint presentation. The presentation will mention why the SEP is necessary regarding the current care for
the AMD members, lay out the pros and cons of maintaining the current practice, the potential benefits of implementing the new programme, what is to be accomplished and how the innovation will outweigh the cost. It will also address the clinical effectiveness of SEP from previous studies, programme transferability and feasibility, estimated cost, and the minimum impact on frontline practice and workload. After successful endorsement, the working group will start the SEP project. Before the pilot study, the group will proceed to refine the relevant programme contents according to feedbacks from the members of the Service Meeting as well as some frontline staff.

**To guide the change.** In facilitating the change, empowerment and guidance is important to give the frontline staff with confidence to deliver the practice. Therefore before the pilot study, there will be one training session given to the staff, both the nurses and the occupational therapist who are going to lead the SEP, of Health Centre A. The training session will aim at offering the frontline staff with an understanding and skills about the principles and practice of SEP and will remind the shared values and beliefs of the EHS regarding quality service. (The above processes correspond to the 8-week ‘preparation and training’ phase in the full schedule of the SEP project. Figure 3 illustrates the phase in details). Following the pilot study will be two other sharing sessions to update and prepare
the staff for the main study (Health Centre A and Health Centre B). The sharing will include experience sharing from the pilot study (by the staff of Health Centre A), clients and staff feedback regarding the protocol and successful stories and will give positive reinforcement in order to enrich the experience of the attending staff and to prompt changing positive. Moreover, the sharing sessions will simultaneously address revisions made for fine tuning the clinical practice following the evidence and feedback collected from the pilot study. For material support, the working group will devise beforehand a user-friendly manual and produce education materials including a set of power-point teaching slides and relevant pamphlets. After all, from the beginning of and during the project period, the working group will be the body overseeing the implementation process and will give relevant advice and guidance in time when necessary.

**To sustain the change.** Work satisfaction and continuous support is necessary to sustain changes. The project will encourage the nursing officers in Health Centre A and Health Centre B to provide a ‘safe forum’ for their staff to express feelings concerning implementation of the SEP, to share constant support and to receive genuine feedback. The SEP working group will keep on communicating with the nursing officers and try to tease out the encountered problems and address them in advance. Also, there will be a feedback collection
sheet available at the end of the manuals to facilitate staff suggestions. In order to facilitate the compliance of change, the working group will suggest the administrators to allow rooms for adjustment for the frontline service and workload in Health Centre A and Centre B during the pilot and main study periods.

**Pilot Study Plan**

**Purpose**

The purpose of the pilot study is to examine the work flow of the SEP, the validity of measuring tools and the feasibility in the local setting. It also enables evaluation and to receive recommendations in order to determine whether revisions are needed before implementing the SEP guidelines to other clinically appropriate units.

**Design**

The SEP is a pre-test and post-test design. All recruited clients will receive the SEP on a weekly basis from week 1 to week 6. Data to collect will come from the same group of clients before intervention (the first session) and six weeks after the intervention.
Setting

Elderly Health Centre A will be the pilot centre.

Subject Recruitment

The SEP will recruit four to ten elders with AMD from Health Centre A according to the inclusion criteria stated in the evidence-based clinical guideline developed (recommendation 1.0). The nature of the participants will be the same as that in the main study and the evaluation plan in the next chapter will cover the details. For the examination, the nurses will assess the vision condition and screen for AMD for the clients coming for annual assessment in the morning session. The nurses will then invite the eligible clients to join the SEP. The subject recruitment procedure will take approximately 4 weeks to complete.

Intervention

The pilot plan will deliver one SEP group according to the evidence-based guideline developed. The programme will be 6 weeks in length in weekly 2-hour sessions plus a home visit. Staff, either a registered nurse trained in public health programmes or a nurse who is experienced with public health background and an occupational therapist offering the home visit, from Health Centre A will lead the SEP. The group should be in four to ten participants. The group leader (the nurse) will make biweekly telephone calls during the follow-up (six weeks) period after
the completion of the programme to keep participants engaged in the programme and to gain their co-operation in completing the programme evaluation.

Measurements

Besides completing the pre-test and post-test evaluation for the programme effectiveness, the study will explore two outcomes, ‘client satisfaction’ and ‘staff satisfaction’, for the process evaluation. Appendix I and Appendix J showed the relevant tools designed by the SEP proposer for the measurements. The study will also estimate a system outcome ‘utilization rate of the innovation’ in the process evaluation. The next chapter will describe details regarding measurement of the outcomes.

Program Refinement

Should there be unsatisfactory evaluation items collected from the pilot evaluation, the working group will arrange remedial adjustment work where necessary.

Conclusion

The above has described the communication process in a top-down approach and the brief ideas regarding the components in the pilot study. Plans to
initiate, to guide and to sustain the change has been addressed. Chapter 5 will cover details for the evaluation plan.
Chapter 5: Evaluation Plan

The purpose of the evaluation plan is for determining the effectiveness of the SEP in the local settings (Health Centre A and Health Centre B) and providing the basis for SEP adoption. It also offers to identify the need, if any, and receives recommendations for performing refinements of the programme where necessary. This chapter will give the descriptions about (a) the outcomes to be achieved, (b) sample size determination, (c) nature of study participants and (d) the basis for adopting the SEP.

Outcomes to be Achieved

The impact evaluation in the main study will measure the two substantial clinical outcomes ‘emotional distress’ and ‘self-efficacy’. The process evaluation will explore the outcomes ‘client satisfaction’, ‘staff satisfaction’ and the ‘utilization rate of the innovation’. To be explicit, the following accounts for each outcome’s (a) specific purpose of measurement, (b) time of measurement, (c) data collection method, (d) data analysis and (e) the basis for effectiveness. For the data analysis, how the data will be statistically analysed depends on the type of outcomes.
to take and the design in collecting the data.

**Emotional Distress (for impact evaluation)**

**Purpose of measurement.** To evaluate the substantial clinical benefits for the local setting

**Time of measurement.** In the first programme session at week 1 for baseline, and at six weeks (week 12) after the intervention for evaluation

**Data collection method.** Using the questionnaire Profile of Mood States (short form) (POMS-SF). The programme implementer (nurse) will administer the tool to get rid of participants’ visual problem in completing the questionnaire.

**Data analysis.**

**Data collection design.** All recruited clients will receive the SEP on a weekly basis from week 1 to week 6. The programme implementer (nurse) will collect the data at week 1 (pre-test) as baseline and at week 12 for evaluation (post-test).

**Data to collect.** Total POMS scores

**Evaluation objective.** To determine if the mean total score is reduced

**Method of analysis.** It requires significance testing using a two-tailed paired (one-sample) t-test at the 6th week follow-up.

**Basis for effectiveness.** Seven units of reduction in the mean total score
in POMS-SF

**Self-efficacy (for impact evaluation)**

**Purpose of measurement.** To evaluate the substantial clinical benefits for the local setting

**Time of measurement.** In the first programme session at week 1 for baseline, and at six weeks (week 12) after the intervention for evaluation

**Data collection method.** Using the Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ) (Brody et al., 2012; Brody et al., 2011; Brody et al., 2002; Brody et al., 2006; Brody et al., 2005; Brody et al., 1999) (Appendix F). The programme implementer (nurse) will administer the tool with the same reason as for the POMS-SF.

**Data analysis.**

*Data collection design.* All recruited clients will receive the SEP on a weekly basis from week 1 to week 6. The programme implementer (nurse) will collect the data at week 1 (pre-test) as baseline and at week 12 for evaluation (post-test).

*Data to collect.* Total AMD-SEQ scores

*Evaluation objective.* To determine if the mean total score is increased

*Method of analysis.* It requires significance testing using a two-tailed
paired (one-sample) t-test at the 6th week follow-up.

**Basis for effectiveness.** Five units of increase in the mean total score in AED-SEQ

The process evaluation involves documentation and record keeping regarding the implementation progress and examination of challenges and barriers to implementation, so as to refine the upcoming plans as indicated.

**Client Satisfaction (for process evaluation)**

**Purpose of measurement.** To determine the effectiveness in programme design as for the target participants, and to identify the need for programme refinement where indicated.

**Time of measurement.** Since fresh memory should increase accuracy, the programme implementer (nurse) will collect the data immediately at the end of the last session at week 6.

**Data collection method.** Using a satisfaction questionnaire (Appendix I) which is to be finalized by the working group. The programme implementer (nurse) will administer the questionnaire to get rid of participants’ visual problem in completing it. The questionnaire includes three parts, presenting items measured on a four-Likert scale: “strongly disagree”, “disagree”, “agree” and “strongly agree” and 3 open questions. The four scale options are coded with
scores 1 to 4 respectively for data entry. For the questions, the first part consists of 5 items assessing clients’ satisfaction about the SEP content.; the second part consists of 3 items assessing clients’ satisfaction on programme arrangements; the third part consists of 5 items assessing clients’ overall perception about the intended benefits of the SEP. Finally, the SEP programme proposer will gather all the completed questionnaires from the two EHCs and perform data analysis.

Data analysis.

Data collection design. All recruited clients will have to complete the programme intervention. The programme implementer (nurse) will collect the data at the end of the last session (post-test) at week 6.

Data to collect. Total satisfaction score

Evaluation objective. To estimate the satisfaction mean score

Method of analysis. It requires estimation using a 95% confidence interval.

Basis for effectiveness. An acceptable mean score of at least 3

Staff Satisfaction (for process evaluation)

Purpose of measurement. To determine the effectiveness in programme design as for the guideline users, and to identify the need for programme refinement where indicated.
**Time of measurement.** The programme implementer (nurse) will complete and collect the data right after finishing the last programme session at week 6.

**Data collection method.** Using a satisfaction questionnaire (Appendix J) which is to be finalized by the working group. The questionnaire includes three parts. The first part consists of 5 items measured on a four-point Likert scale: “strongly disagree”, “disagree”, “agree” and “strongly agree”. This part assesses the healthcare providers’ perception on workload, satisfaction, additional skills gain, knowledge gain and confidence over the implementation of the programme. The second part invites open comments and consists 3 items assessing the adequacy, comprehensiveness and clarity of the programme, on the same four-point Likert scale as in the first part. The third part consists of 1 item assessing staff’s perception on the usefulness of training sessions provided and another item inviting overall comments regarding the programme. Finally, the SEP programme proposer will gather all the completed questionnaires from the two EHCs and perform data analysis.

**Data analysis.**

**Data collection design.** The programme implementer (the nurse) will have to finish the required programme sessions and then collect the data at the end of the last session (post-test) at week 6.
Data to collect.  Total satisfaction score

Evaluation objective.  To estimate the satisfaction mean score

Method of analysis.  It requires estimation using a 95% confidence interval.

Basis for effectiveness.  An acceptable mean score of at least 3

Utilization Rate of the Innovation (for process evaluation)

Purpose of measurement.  To record and monitor the programme utilization rate in Health Centre A and Health Centre B as well as to determine the effectiveness of resource utilization.

Time of measurement.  At week 6 after finishing the programme

Data collection method.  The programme implementer (nurse) will retrieve data from the recruitment record and the attendance record.

Data analysis.

Data collection design.  Clinic staff will look for a pool of eligible clients in the clinic before the programme begins according to the recruitment criteria. At the programme end, the nurse implementer will have to count the number of participants completing the programme with an attendance rate of at least 80%.

Data to collect.  The number of clients participated in the programme
against the number of clients completing the programme (with an attendance rate of at least 80%).

Evaluation objective. To estimate the proportion of clients in the SEP who finally complete the programmes (with an attendance rate of at least 80%).

Method of analysis. It requires estimation using a 95% confidence interval.

Basis for effectiveness. A reasonable utilization rate of not less than 0.8

To conclude, Table 5 presented a summary table for the evaluation of outcomes in the main study.

Sample Size Determination

First, in the main study, ‘emotional distress’ is the primary outcome determining the sample-size estimates. As stated earlier in the evaluation plan, the analysis involves significance testing using a two-tailed paired (one-sample) t-test (to determine the reduction in mean total score (evaluation objective) with the collection of the data (total POMS scores) before and after the programme intervention from the same group of elders who are to receive the SEP). Second, to the effect size as bounded by the evidence reviewed which has been discussed
in the data synthesis previously, the SEP proposer will consider a reduction of 7 units in the mean total score in POMS as reaching the bottom-line effect (short-term) for programme effectiveness. Third, for sigma (standard deviation), the estimation will use a value of 21.83 POMS score (Brody et al., 2002). Hence, by using the computer software Java Applets for Power and Sample Size (Lenth, 2011), based on one-sample paired t-test analysis with 2-sided significance level of 0.05, achieving 80% statistical power to detect 7 units of reduction in the mean total score in POMS at the 6th week follow-up after completion of the intervention, the evaluation will require a sample size of 78 elders. Finally, assuming a 20% dropout rate, the main study will recruit 98 participants. To this, Health Centre A and Health Centre B need to recruit an average of 49 participants respectively. Thus, each of the two health centres should conduct about five SEP groups (4-10 persons per group) to recruit adequate participants. Since centre A and centre B will simultaneously provide the SEP on quarterly basis, it will take eventually less than 1.5 years (71 weeks) to finish the main study. Participant recruitment will take place continually throughout the main study period. Figure 4 illustrates the schedule for the main study.

Nature of Study Participants
The study will include community-dwelling elders who are the enrolled members in either Health Centre A and Health Centre B. SEP participants must be aged 65 years or above and are experiencing vision impairment or vision loss due to AMD. For inclusion in the study, their visual acuity have to reach 20/60 (or 0.5 in LogMAR values) or worse in the better eye and 20/100 (or 0.7 in LogMAR values) or worse in the other eye under habitual correction by current glasses. Moreover, it has to be affirmed that AMD is a principal cause for the visual disability of the individual elders.

**Basis for Adopting the Innovation**

The content below concludes the basis on which the SEP guideline will be considered as effective. Attaining the basis in the results of the main study means that the SEP is favorable for being adopted as a new educational programme in the Elderly Health Service for those elderly members with AMD.

**Substantial Clinical Outcomes**

The chief indication of SEP effectiveness is the achievement of the defined substantial clinical outcomes. The reviewed studies used ‘emotional distress’ as a
primary outcome and ‘self-efficacy’ as a secondary outcome to reflect programme effectiveness. These chosen outcomes were associated with consistent findings among studies of 1++ evidence level. As bounded by the evidences, achieving programme effectiveness in the local setting will mean reaching a bottom-line effect of 7 units of reduction in mean total score for ‘emotional distress’ (Brody et al., 2002), and 5 units of increase in mean total score for ‘self-efficacy’ (Brody et al., 2002).

Client Outcomes from the Process Evaluation

As for the target participants, the satisfaction mean score is an indication of effectiveness in the design of the programme. As described in the evaluation plan, the Client Satisfaction Questionnaire (Appendix I) will measure a total satisfaction score for each participant for the estimation of satisfaction mean score. Hence, with the scoring scale of the questionnaire, a client satisfaction mean score of at least 3, together with a total questionnaire response rate of not less than 80%, will reflect the achievement in programme effectiveness regarding client perspectives.

Healthcare Provider Outcomes from the Process Evaluation

As for the guideline users, the satisfaction mean score is an indication of effectiveness in the design of the programme. Similarly, the Evaluation
Questionnaire For Staff (Appendix J) will measure a total satisfaction score for each programme implementer for the estimation of satisfaction mean score. A staff satisfaction mean score of at least 3, together with a total questionnaire response rate of not less than 80%, will reflect the achievement in programme effectiveness regarding programme implementers’ perspectives.

System Outcome from the Process Evaluation

The utilization rate of the innovation is an indicator reflecting the effectiveness of resource use. In this project, the definition of utilization rate is the proportion of clients in the SEPs who finally complete the SEP programmes with an attendance rate of at least 80%. An utilization rate of 0.8 or more will reflect effective programme utilization.

Conclusion

The chapter has specified the conditions that determine the effectiveness of the SEP in Health Centre A and Health Centre B and has provided the basis for adoption of the SEP for the local setting. The above has described the evaluation for the five outcomes to be achieved in the main study, explained the process of sample size determination, stated the nature of study participants and concluded
the basis for adopting the SEP.
Chapter 6: Conclusion

This paper has gone through a process in developing an evidence-based clinical guideline about Self-management Education Programme (SEP) for older adults with age-related macular degeneration (AMD) in the local setting, Elderly Health Centre A and Elderly Health Centre B, in the form of a translational research proposal. The paper gathered empirical evidence on the effectiveness of SEP in providing better health outcomes for the older adults with AMD, conducted a quality assessment of previous studies, determined the implementation potential of SEP for the local setting, developed clinical guidelines and described the implementation and evaluation plan of the SEP. Considering the adoption of the developed guidelines in the local setting will optimistically improve the emotional status and self-efficacy of elderly patients suffering from AMD, mediating the negative impacts of vision impairment or vision loss on their quality of life.
References


Brody, B. L., Williams, R. A., Thomas, R. G., Kaplan, R. M., Chu, R. M., &

Centre for Reviews and Dissemination. (2011). Reviews abstract:


### Figure 1. A Full Schedule for the SEP Project (consisted Pilot and Main Studies) for Health Centre A and Health Centre B

1 Preparation & Training: proposing a new topic and lesson plan; communication with administrators and staff; drafting and refining programme contents; resource production & gathering of teaching aids/tools; training staff for the pilot study for Health Centre A.

2 Pilot Study: (a) Participants recruitment (b) Implementation of the 6-week programme with pre-intervention measure (c) Post-intervention measure, data collection and analysis.

3 Reporting: dissemination of results on the pilot study and main study.
<table>
<thead>
<tr>
<th>Session</th>
<th>Week</th>
<th>Topics</th>
<th>Hours</th>
<th>Remarks</th>
</tr>
</thead>
</table>
| 1       | Week 1 | 1. The AMD disease  
2. Understanding problems due to vision loss:  
   - loss of depth perception/ loss of contrast sensitivity/colour or distance problems/ seeing spots that block central vision/ restricted peripheral vision/ inability to see and identify faces  
   #Baseline assessment of programme indicators emotional distress & self-efficacy by questionnaires POMS-SF & AMD-SEQ (Appendix F) at the class beginning | 2-hr | 5 hours of homework per week at home to practice performing everyday tasks & use of adaptive devices |
| 2       | Week 2 | 3. Coping strategies for AMD vision problems:  
   - staying positive & setting realistic goals/ adjusting & active learning new skills/ feeling empowered through accomplishment/ keeping things in perspective/ accepting limitations/ avoid being too demanding of oneself/ active seeking support/ adopting a ‘can do’ attitude/ asking for assistance | 2-hr | (Self-directed learning, skills training)  
   *: To perform Client Satisfaction Questionnaire (Appendix I) at the end of the 6th session in week 6 |
| 3       | Week 3 | 4. Enhance capacity and maintain active living  
   - information on lighting options/ getting organized for dependence/ keeping things in the same place/ modifying everyday items e.g. large print, contrasting colours and tactile markings/adaptive devices | 2-hr |  |
| 4       | Week 4 | 5. Practical tips/ skills (Appendix G)  
   - BasicTips: improve lighting/ control glare/ enlargement/label | 2-hr |  |
<table>
<thead>
<tr>
<th>Week 2-6</th>
<th>9. One home visit by an occupational therapist: - home environment modification / daily activities organization/ use of adaptive devices</th>
<th>About 1 hr</th>
</tr>
</thead>
<tbody>
<tr>
<td>Week 7-12</td>
<td>Biweekly phone calls</td>
<td>-</td>
</tr>
<tr>
<td>Week 12</td>
<td>*Evaluation of programme indicators emotional distress &amp; self-efficacy by questionnaires POMS-SF &amp; AMD-SEQ (Appendix F)</td>
<td>2-hr Brief reunion</td>
</tr>
<tr>
<td>Booster session (optional)</td>
<td>the sixth month from week 6 Condensed content from the six-week programme; exchange of daily experience; skills consolidation</td>
<td>2-hr</td>
</tr>
</tbody>
</table>
## Figure 3. The Eight-week Preparation and Training Phase for the SEP Project

Notes: (I) Communication with peer colleagues; (II) Communication with administrators; (III) Proposal of a new topic and lesson plan; (IV) Preparation and refinement of programme contents and production of education resources; (V) Collection of teaching materials and aids/tools; (VI) Equipment of staff for the pilot study
| Week | 0-4 | 8 | 12 | 16 | 20 | 24 | 28 | 32 | 36 | 40 | 44 | 48 | 52 | 56 | 60 | 64 | 68 | 70 | 72 |
|------|-----|---|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|----|
| Activities | | | | | | | | | | | | | | | | | | | |
| Recruitment of Participants | | | | | | | | | | | | | | | | | | | |
| Implementation of Programmes with Pre- & Post-intervention Measures | | | | | | | | | | | | | | | | | | | |
| Data Collection & Analysis | | | | | | | | | | | | | | | | | | | |
| Report Preparation | | | | | | | | | | | | | | | | | | | |
| Dissemination of Results | | | | | | | | | | | | | | | | | | | |

**Figure 4. A Schedule for the Main Study**

1. Implementation of Programmes with Pre- & Post-intervention Measures: simultaneous SEPs in Centre A and Centre B on a quarterly basis.
2. Data Collection & Analysis: a total of 10 sets of pre-post data from Centre A and Centre B are collected altogether for analysis.
### Table 1
**Results from the Searching and Screening Process**

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<th>#</th>
<th>Search terms / screening process</th>
<th>Ovid MEDLINE(R) (from 1948 to July 2011)</th>
<th>CINHAL Plus (from 1937 to August 2011)</th>
<th>EMBASE (classic + from 1947 to September 2011)</th>
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<td>81084</td>
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<td>-</td>
<td>316290</td>
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<td>5</td>
<td>1 AND (2 OR 3) AND 4</td>
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<td>Excluding duplicates within the individual database</td>
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<tr>
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<td>Screening titles and abstracts using the study selection criteria</td>
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<td>No. of session spent per SEP</td>
<td>Unit cost (HK$)</td>
<td>Production cost (HK$) (to the nearest hundredth)</td>
</tr>
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</tr>
<tr>
<td>RN</td>
<td>1</td>
<td>366,000</td>
<td>744</td>
<td>32.73</td>
<td>24,400</td>
</tr>
<tr>
<td>OT</td>
<td>1</td>
<td>351,600</td>
<td>715</td>
<td>2</td>
<td>1,400</td>
</tr>
<tr>
<td>GD</td>
<td>1</td>
<td>294,000</td>
<td>800 (per day)</td>
<td>3</td>
<td>2,400</td>
</tr>
</tbody>
</table>

attributed by emoluments

attributed by materials $a\times c\times d$

### (A) Generating SEP programme contents (Master Kit)

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
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</tr>
</thead>
<tbody>
<tr>
<td>Master Kit:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- education materials, pamphlets, VCD</td>
<td>1</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>4,000</td>
</tr>
<tr>
<td>Low-vision adaptive devices</td>
<td>3</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>500</td>
</tr>
</tbody>
</table>

attributed by emoluments

attributed by materials $a\times e$

### (B) Pilot project in Centre A

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>RN (running the pilot)</td>
<td>1</td>
<td>366,000</td>
<td>744</td>
<td>6</td>
<td>4,500</td>
</tr>
<tr>
<td>OT (home visit)</td>
<td>1</td>
<td>351,600</td>
<td>715</td>
<td>1</td>
<td>700</td>
</tr>
<tr>
<td>RN (report)</td>
<td>1</td>
<td>366,000</td>
<td>744</td>
<td>8</td>
<td>6,000</td>
</tr>
<tr>
<td>RN (training)</td>
<td>90</td>
<td>366,000</td>
<td>744</td>
<td>1</td>
<td>67,000</td>
</tr>
<tr>
<td>RN (kit modification)</td>
<td>1</td>
<td>366,000</td>
<td>744</td>
<td>6</td>
<td>4,500</td>
</tr>
</tbody>
</table>

attributed by emoluments

attributed by materials $a\times e$

### (C) Replicating resource copies (duplicated kits)

<p>| | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Kit copies:</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- education materials, pamphlets, VCD</td>
<td>18</td>
<td>-</td>
<td>-</td>
<td>-</td>
<td>1,300</td>
</tr>
</tbody>
</table>

attributed by emoluments

attributed by materials $a\times e$

### (D) Total Non-recurrent Cost (HK$)

158,300
Table 3
Estimation for the Recurrent (Operating) Cost Per Annum Under the Elderly Health Service (EHS)

<table>
<thead>
<tr>
<th>Full scale implementation (in 18 health centres) of SEP in the Elderly Health Service (EHS)</th>
<th>No. per SEP</th>
<th>Cost per working session (HK$)</th>
<th>No. of session spent per SEP</th>
<th>No. of SEP delivered in EHS per year</th>
<th>Unit cost (HK$)</th>
<th>Annual cost (HK$) (to the nearest hundredth)</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>$g$</td>
<td>$h$</td>
<td>$i$</td>
<td>$j$</td>
<td>$k$</td>
<td>$l = g \times h \times i \times j$</td>
</tr>
<tr>
<td>RN</td>
<td>1</td>
<td>744</td>
<td>7#</td>
<td>72</td>
<td>-</td>
<td>375,000</td>
</tr>
<tr>
<td>OT (home visit)</td>
<td>1</td>
<td>715</td>
<td>1</td>
<td>72</td>
<td>-</td>
<td>51,500</td>
</tr>
<tr>
<td>Patient education materials, homework, assessment forms, etc</td>
<td>-</td>
<td>-</td>
<td>72</td>
<td>50</td>
<td>3,600</td>
<td></td>
</tr>
<tr>
<td></td>
<td>(E)</td>
<td></td>
<td></td>
<td></td>
<td>430,100</td>
<td></td>
</tr>
</tbody>
</table>

# Included 6 teaching sessions and 1 session for post-evaluation with reunion.
Table 4  
*Estimation for the Potential Benefits of SEP in A Year (based on geriatric depression avoided)*

<table>
<thead>
<tr>
<th>HA service demanded per new incidence of depressive AMD patient</th>
<th>Cost per attendance (HK$)</th>
<th>No. of visit in a year</th>
<th>Total service cost per patient in a year (HK$)</th>
</tr>
</thead>
<tbody>
<tr>
<td>GOPC service*</td>
<td>310</td>
<td>1</td>
<td>1,260</td>
</tr>
<tr>
<td>SOPC service*</td>
<td>950</td>
<td>1</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Incidence of geriatric depression avoided</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Total no. of SEP participants in a year in EHS</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>SEI prevention rate for geriatric depression in AMD patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total no. of elders being prevented from depression in the year</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>(G) Potential benefits (savings) in a year (m*n)</td>
<td>HK$ 90,720</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

*GOPC: general outpatient clinic ; *SOPC: specialist outpatient clinic

<table>
<thead>
<tr>
<th>EHS service demanded per new incidence of depressive AMD patient</th>
<th>Annual salary, mid-point (HK$)</th>
<th>Cost per hour of consultation (HK$)</th>
<th>Estimated no. of consultation (20 mins) per patient in a year</th>
<th>Estimated cost of consultation per patient in a year (HK$) (p)</th>
<th>Total no. of elders being prevented from depression by the programme in a year (n)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Clinical psychologist (CPY) consultation</td>
<td>688,300</td>
<td>300</td>
<td>2</td>
<td>200</td>
<td>72</td>
</tr>
</tbody>
</table>

(H) Potential benefits (savings) in a year (p*n) HK$ 14,400

<table>
<thead>
<tr>
<th>Other health costs and social costs</th>
<th>Estimated average cost avoided per elders due to low vision problem in a year (HK$) (q)</th>
<th>Total no. of AMD participants in a year in EHS (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hospitalization cost/ drug cost/ social service and welfare cost/ caring cost from informal carers/ cost of falls &amp; home accidents/ demand for home care services/ emergency care/ residential care services</td>
<td>7,000</td>
<td>720</td>
</tr>
</tbody>
</table>

(I) Potential benefits (savings) in a year (q*r) HK$ 5040,000
Table 5
A Summary Table for the Outcomes to Measure in the Main Study for the SEP Programme

<table>
<thead>
<tr>
<th>Purpose of Measurement</th>
<th>Outcome Identified</th>
<th>Time of Measurement (When to take)</th>
<th>Data Collection Method (How to take / by what means)</th>
<th>Data Analysis Basis to be considered as effective?</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Client Outcomes (substantial clinical benefits) Measurement</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>To evaluate the substantial clinical benefits in Health Centre A and Health Centre B</td>
<td>Emotional Distress (POMS score)</td>
<td>WEEK1 (baseline) &amp; WEEK 12 (six weeks after intervention)</td>
<td>By questionnaire: Profile of Mood States (POMS-SF); nurse-administered</td>
<td>-All recruited clients to receive the SEP on a weekly basis from WEEK 1 to WEEK 6 -Data to be collected at WEEK 1 (pre-test) and WEEK 12 (post-test)</td>
</tr>
<tr>
<td></td>
<td>Self-Efficacy (AMD-SEQ score)</td>
<td></td>
<td>By questionnaire: Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ); nurse-administered (Appendix F)</td>
<td>Total POMS scores</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
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<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Purpose of Measurement</td>
<td>Outcome Identified</td>
<td>Time of Measurement (When to take)</td>
<td>Data Collection Method (How to take / by what means)</td>
<td>Data Analysis</td>
</tr>
<tr>
<td>------------------------</td>
<td>-------------------</td>
<td>-----------------------------------</td>
<td>---------------------------------------------</td>
<td>---------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Design (How to collect data)</td>
<td>Outcome to take</td>
</tr>
<tr>
<td>Client Satisfaction Measurement (process evaluation)</td>
<td></td>
<td></td>
<td>Total satisfaction score</td>
<td>To estimate the satisfaction mean score</td>
</tr>
<tr>
<td>-To determine the effectiveness in programme design as for the target participants. -To identify the need for programme refinement where indicated</td>
<td><strong>Client Satisfaction</strong></td>
<td>WEEK 6 (at the end of the last session)</td>
<td>By questionnaire; nurse-administered (Appendix I)</td>
<td>-All recruited clients to complete programme intervention - Data to be collected at the end of the last session</td>
</tr>
<tr>
<td>Healthcare Provider Outcomes (process evaluation)</td>
<td></td>
<td></td>
<td>Total satisfaction score</td>
<td>To estimate the satisfaction mean score</td>
</tr>
<tr>
<td>-To determine the effectiveness in programme design as for the guideline users. -To identify the need for programme refinement where indicated</td>
<td><strong>Staff Satisfaction</strong></td>
<td>WEEK 6 (at the end of the last session)</td>
<td>By questionnaire (Appendix J)</td>
<td>Programme implementer (nurse) to finish the required sessions - Data to be collected at the end of the last session</td>
</tr>
<tr>
<td>Purpose of Measurement</td>
<td>Outcome Identified</td>
<td>Time of Measurement (When to take)</td>
<td>Data Collection Method (How to take / by what means)</td>
<td>Data Analysis</td>
</tr>
<tr>
<td>------------------------</td>
<td>--------------------</td>
<td>------------------------------------</td>
<td>------------------------------------------------------</td>
<td>--------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td>WEEK 6 (after finishing the programme)</td>
<td>Referring data in the recruitment record &amp; attendance record</td>
<td></td>
</tr>
<tr>
<td>-To record and monitor programme utilization rate in Health Centre A and Health Centre B</td>
<td><strong>Utilization of the Innovation</strong></td>
<td></td>
<td>-Beginning: staff to look for a pool of eligible clients in the clinic according to recruitment criteria -Programme end: staff to count the no. of participants completing the programme with an attendance rate of 80% or above</td>
<td>Total no. of clients completing the programme (with an attendance rate of at least 80%); and total no. of clients ever participated in the SEP groups</td>
</tr>
<tr>
<td></td>
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<td></td>
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<tr>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>
### TABLES OF EVIDENCE

#### TABLE OF EVIDENCE 1 of 9 (Randomized Controlled Trial)

<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95%CI, significant level p= 0.05 other than specified )</th>
</tr>
</thead>
<tbody>
<tr>
<td>Brody et al., 2002 (RCT)</td>
<td>Age, mean 80.89 yr</td>
<td>n=86 in analysis (n=92 from randomization)</td>
<td>n=145 in analysis (n=160 from randomization)</td>
<td>Primary (1) <strong>Emotional distress</strong>&lt;br&gt;  - By Profile of Mood States (POMS)¹; self-report</td>
<td>At 6th week follow-up (short-term)</td>
<td>Primary (1) Diff. in mean total score of POMS&lt;br&gt; Rx: -7.09 (SD 21.83), CI -15.39 to -1.21; Control: 3.41 (SD 21.54), CI -2.39 to 9.21 (p=.02)</td>
</tr>
<tr>
<td></td>
<td>Male 33.8%</td>
<td>Program Self-management program</td>
<td>Control A Tape-recorded lectures, n=79, 6 wks (weekly 2-hr tape lectures, totally 12-hr)</td>
<td>Secondary (2) <strong>Vision-dependent function</strong>&lt;br&gt;  - By National Eye Institute Visual Function Questionnaire (NEI-VFQ)²; interviewer-administered</td>
<td></td>
<td>Secondary (2) Diff. in mean total score of NEI-VFQ&lt;br&gt; Rx: 1.02 (SD 6.8), CI -0.44 to 2.48; Control: 0.07 (SD 7.5), CI 1.16 to 1.31 (p=.04)</td>
</tr>
<tr>
<td></td>
<td>Unskilled or semiskilled workers 14.85%</td>
<td>Duration 6 wks (weekly 2-hr group sessions, totally 12 hr)</td>
<td>Control B Waiting list n=81</td>
<td>(3) <strong>Self-efficacy</strong>&lt;br&gt;  - By Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ)³; self-report</td>
<td></td>
<td>(3) Diff. in mean total score of AMD-SEQ&lt;br&gt; Rx: 5.34 (SD 12.17), CI 2.73 to 7.95; Control: 1.12 (SD 11.85), CI 0.82 to 3.07 (p=.02)</td>
</tr>
<tr>
<td></td>
<td>Living alone 36.6%</td>
<td>Components 1. Didactic presentation on disease information 2. Problem-solving 3. Cognitive skills training 4. Behavioral skills training</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Log of best eye, mean 1.11; 65% legally blind ⁴</td>
<td></td>
<td></td>
<td></td>
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</tr>
<tr>
<td></td>
<td>Time since diagnosis, mean 97.26 mon</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Depressed subjects 24%</td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

* Data associated with significantly favorable result(s) are in **bolded** letters.

¹ POMS: assessed emotional distress in 65 items.

² NEI-VFQ: assessed health-related quality of life in relation to vision, in 25 items with appendixes of optional additional questions.

³ AMD-SEQ: evaluated the degree of self-confidence in an individual’s ability to handle situations related to AMD, in 13 items.

⁴ Log value ≥1.000 equals legal blindness.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI, significant level p= 0.05 other than specified )</th>
</tr>
</thead>
</table>
| Brody et al., 2005 (RCT) | ● Age, mean 80.82 yr  
● Male 32.2%  
● Education, mean 13.76 yr range 3-21 yr  
● Unskilled or semiskilled workers 14.95%  
● Living alone 37.4%  
● Log of best eye, mean 1.11; 76.7% legally blind  
● Time since diagnosis, mean 92.43mon  
● Depressed subjects 23.8% | n=82 in analysis (n=92 from randomization)  
Program: Self-management program  
Duration: 6 wks (weekly 2-hr group sessions, totally 12-hr)  
Components: 1. Didactic presentation on disease information  
2. Problem-solving  
3. Cognitive skills training  
4. Behavioral skills training | n=132 in analysis (n=160 from randomization)  
Control A: Tape-recorded lectures, n=79, 6 wks (weekly 2-hr tape lectures, totally 12-hr)  
Control B: Waiting list n=81 | Primary  
(1) **Emotional distress**  
● By Profile of Mood States (POMS)1; self-report  
Secondary  
(2) **Vision-dependent function**  
● By National Eye Institute Visual Function Questionnaire (NEI-VFQ)2; interviewer-administered  
(3) **Self-efficacy**  
● By Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ)3; self-report  
(4) **Incidence of clinical depression**  
● By Structured Clinical Interview for Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition, research version (SCID)4; interviewer-administered | At 6th month follow-up (medium-term) | Primary  
(1) Diff. in mean total score of POMS  
Rx: -11.64 (SD 25.60), CI -17.28 to -6.01;  
Control: 0.14 (SD 21.55), CI -3.85 to 3.57 (p=.008)  
Secondary  
(2) Diff. in mean total score of NEI-VFQ  
Rx: 2.64 (SD 9.07), CI -0.69 to 4.67;  
Control: 0.01 (SD 8.04), CI 1.37 to 1.38 (p=.05)  
(3) Diff. in mean total score of AMD-SEQ  
Rx: 7.54 (SD 13.71), CI 4.49 to 10.59;  
Control: 1.90 (SD 1.20), CI 0.03 to 3.83 (p=.006)  
(4) Relative ratio 0.49, CI 0.25 to 0.97 (p=.05) |

* Data associated with significantly favorable result(s) are in **bolded** letters.
1 POMS: assessed emotional distress in 65 items.
2 NEI-VFQ: assessed health-related quality of life in relation to vision, in 25 items with appendixes of optional additional questions.
3 AMD-SEQ: evaluated the degree of self-confidence in an individual’s ability to handle situations related to AMD, in 13 items.
4 SCID: identified major and minor symptomatic depression.
5 Log value ≥1.000 equals legal blindness.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (significant level p= 0.05 other than specified )</th>
</tr>
</thead>
</table>
| Brody et al., 2006 (RCT) (A follow-up study of Brody et al., 2002) | ● Age, mean 81.53 yr  
● Male 34.4%  
● Education, mean 14.03 yr  
● Unskilled or semiskilled workers 15.6%  
● Living alone 53.1%  
● Log of best eye, mean 1.26; 59.3% legally blind  
● Time since diagnosis, mean 50.76mon  
● **Depressed subjects** 100%  | n=12  
Program  
Self-management program  
Duration  
6 wks (weekly 2-hr group sessions, totally 12-hr)  
Components  
1. Didactic presentation on disease information  
2. Problem-solving  
3. Cognitive skills training  
4. Behavioral skills training  | n=20  
Control A  
Tape-recorded lectures, n=79, 6 wks (weekly 2-hr tape lectures, totally 12-hr)  
Control B  
Waiting list  
n=81  | Primary  
(1) **Geriatric depression symptoms**  
● By Geriatric Depression Scales (GDS-15)\(^1\); interviewer-administered  
Secondary  
(2) Vision-dependent function  
● By National Eye Institute Visual Function Questionnaire (NEI-VFQ)\(^2\); interviewer-administered  
(3) **Self-efficacy**  
● By Macular Degeneration Self-Efficacy Questionnaire (AMD-SEQ)\(^3\); self-report  | At 6\(^{th}\) month follow-up (medium-term)  | Primary  
(1) Diff. in mean total score of GDS-15  
Rx: -2.92 (SD 3.26); Control: -1.00 (SD 3.78) (p=.03)  
Secondary  
(2) Diff. in mean total score of NEI-VFQ  
Rx: 5.7 (SD 13.08); Control: 3.34 (SD 18.65) (p=.21)  
(3) Diff. in mean total score of AMD-SEQ  
Rx: 17.31 (SD 23.30); Control: 3.95 (SD 23.44) (p=.01)  |

* Data associated with significantly favorable result(s) are in **bolded** letters.

\(^1\) GDS-15: assessed the extent of depressive symptoms in 15 items

\(^2\) NEI-VFQ: assessed health-related quality of life in relation to vision, in 25 items with appendixes of optional additional questions.

\(^3\) AMD-SEQ: evaluated the degree of self-confidence in an individual’s ability to handle situations related to AMD, in 13 items.

\(^4\) Log value \(\geq 1.000\) equals legal blindness.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI other than specified)</th>
</tr>
</thead>
</table>
| Dahlin et al., 2002 (RCT) | ● Age, median 79 yrs  
● Visual acuity of best eye, median 0.3 | n=93 in analysis  
(n=123 from randomization) | n=94 in analysis  
(n=130 from randomization) | Perceived security in performance daily activity  
● By a test designed for the study (tested for reliability & validity)\(^1\); self-reported | At 4th month follow-up (short-term) | Change in relative position (RP) in the test: Rx: RP range 0.08 to 0.46, lower CI range 0.02 to 0.30, upper CI range 0.21 to 0.62; Control: RP range -0.16 to 0.15; lower CI range -0.23 to 0.08, upper CI range 0.03 to 0.22 (significantly improved perceived security in performing daily activity in several (13 out of 28) activities in Rx group vs Control group) |

* Data associated with significantly favorable result(s) are in **bolded** letters.  
\(^1\) A test designed for the study: assessed 7 areas of self-care task, in 29 items.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI other than specified )</th>
</tr>
</thead>
</table>
| Eklund et al., 2004 (RCT) (A follow-up study of Dahlin et al., 2002) | • Age, mean 80 yr  
• Male 31%  
• Living alone 60.71%  
• Visual acuity of better eye, median 0.3 | n=62 in analysis  
(n=109 from randomization) | n=69 in analysis  
(n=120 from randomization) | Perceived security in performing daily activities  
• By a test designed for this study\(^1\) (the same instrument used in Dahlin et al., 2002); self-reported | At 28\(^{th}\) month follow-up (long-term)  
(follow-up took place 1, 4, 16, 28 mons after completion of programme) | Change in relative position (RP) in the test :  
Rx: RP range 0.15 to 0.46, lower CI range 0.01 to 0.29, upper CI range 0.3 to 0.63; Control group: RP range -0.32 to -0.14, lower CI range -0.46 to -0.27, upper CI range -0.17 to -0.003  
(significantly improved perceived security in performing daily activity in several (15 out of 28) activities in Rx group vs Control group) |

\(^*\) Data associated with significantly favorable result(s) are in **bolded** letters.  
\(^1\) A test designed for the study: assessed 7 areas of self-care task, in 28 items.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI, significant level p = 0.05 other than specified)</th>
</tr>
</thead>
</table>
| Eklund et al., 2005 (RCT) | ● Age, mean 80 yr  
● Male 31%  
● Living alone 60.71%  
● Visual acuity of better eye, median 0.3 | n=62 in analysis  
(n=109 from randomization) | n=69 in analysis  
(n=120 from randomization) | Perceived security in performing daily activities  
● By a test designed for this study\(^1\) (the same instrument used in Dahlin et al., 2002); self-reported | At 28\(^{th}\) month follow-up (long-term) | Provided additional summative data to Eklund et al., 2004: Significantly improved perceived security in daily activity in 28 subjects (45%) in Rx group vs 7 subjects (10%) in control group, CI 21 to 49 (p=.0001) |
| (Cost-effectiveness analysis study of Eklund et al., 2004) | Program  
Health Education Programme  
Duration 8 wks (weekly 2-hr group session)  
Components  
1. Modeling  
2. Behavioral skill training  
3. Booklets  
4. Problem-solving | Program  
Health Education Programme  
Duration 8 wks (weekly 2-hr group session)  
Components  
1. Modeling  
2. Behavioral skill training  
3. Booklets  
4. Problem-solving | | |

\(^*\) Data associated with significantly favorable result(s) are in bolded letters.

\(^1\) A test designed for the study: assessed 7 areas of self-care task, in 28 items.
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI other than specified)</th>
</tr>
</thead>
</table>
| Eklund et al., 2008 (RCT) | Age, mean 80 yr  
Male 31%  
Living alone 60.71%  
Visual acuity of better eye, median 0.3 | Program Health Education Programme  
Duration 8 wks (weekly 2-hr group session)  
Components 1. Modeling 2. Behavioral skill training 3. Booklets 4. Problem-solving | Control Individual Intervention Programme, (one to two 1-hr session(s), telephone follow-up within 2 to 4 wks) | Primary (1) ADL staircase (i.e. visual-related function)  
A test 1 (but not traceable)  
Secondary (2) General health  
By SF-36 (3) Self-reported health problem  
A test 2 (but not traceable) | At 28th month follow-up (long-term) (follow-up took place 1, 4, 16, 28 mons after completion of programme) | Primary  
(1) Change in relative position (RP) in the test for ADL staircase: Rx: RP 0.11, CI -0.03 to 0.25; Control: RP 0.34, CI 0.24 to 0.46 (i.e. Rx group maintained ADL dependency but control group not)  
Secondary  
(2) Change in RP in SF-36 test: Rx: RP 0.17, CI 0.04 to 0.3; Control: RP 0.34, CI -0.002 to 0.34 (i.e. general health dropped in both groups)  
(3) Change in RP in the self-reported health problem test: Rx: RP -0.15, CI -0.29 to -0.01; Control: RP 0.07, CI -0.05 to 0.18; CI diff. between two groups: 0.04 to 0.4 (i.e. significantly reduced in Rx group vs control group) |

* Data associated with significantly favorable result(s) are in bolded letters.

1 Dependence level in ADL was assessed by a cumulative scale of four well defined instrumental activities (cleaning, shopping, transportation, cooking) combined with five personal activities (bathing, dressing, toilet use, transferring and feeding) by Sonn, U., & Hulters Asberg, K. (1991).

2 The questions have been used in gerontological and geriatric population studies in Gothenburg, Sweden by Steen & Djurfeldt (1993).
<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (significant level p= 0.05 other than specified )</th>
</tr>
</thead>
</table>
| Rovner et al., 2007 (RCT) | - Age, mean 81yr  
- Male 30%  
- Education, mean 12.5 yr  
- Log of best eye, mean 0.60 | n=95 in analysis  
(n=105 from randomization)  
Program Problem-solving treatment (PST)  
Duration 6 in-home PST sessions (45-60 min) during 8 wks  
Components 1. Problem-solving skills 2. Strategies to achieve valued functional goals | n=99 in analysis for short-term effect  
(n=101 from randomization)  
Control Usual care | Primary  
(1) DSM-IV defined diagnosis of major or minor depression  
- By the Hamilton Depression Rating Scale (HDRS)\(^1\); interviewer-administered  
Secondary  
(2) Rate of relinquishing valued activities  
- By the National Eye Institute Vision Function Questionnaire-17 (NEI VFQ-17)\(^2\); self-reported | At 2\(^{nd}\) month (short-term) & 6\(^{th}\) month follow-ups (medium-term) | At 2-mon FU:  
Primary  
(1) Incidence of clinical depression in Rx group vs Control group: Odds Ratio 0.39, CI 0.17 to 0.92 (p=.03)  
Secondary  
(2) Rate of relinquishing valued activities in Rx group vs Control group: Odds Ratio 0.48, CI 0.25 to 0.96 (p=.04) |

* Data associated with significantly favorable result(s) are in **bolded** letters.

1 HDRS: assessed the severity of symptoms of depression in 24 items, scores less than 7 were considered normal (score range 0 to 75).
2 NEI VFQ-17: reported difficulty level on vision-dependent daily activities in 17 items, from a subset of the original NEI VFQ-52.
### TABLE OF EVIDENCE 9 of 9 (Randomized Controlled Trial)

<table>
<thead>
<tr>
<th>Citation (study design)</th>
<th>Subject Characteristics</th>
<th>Intervention</th>
<th>Control</th>
<th>Outcome Measures*</th>
<th>Time of Measurement*</th>
<th>Effect Size* (95% CI, significant level p= 0.05 other than specified )</th>
</tr>
</thead>
</table>
| Stelmack et al., 2008 (RCT) | • Age, mean 78.9 yr  
• Male 97.6%  
• Living alone 24.6%  
• Log of best eye, mean 1.11 | Program  
Low-vision Intervention Trial (LOVIT)  
Duration  
6 wks (5 weekly 2-hr sessions, plus one home visit)  
Components  
1. Education on disease information  
2. Counseling  
3. Strategies in use of remaining vision & low-vision devices  
4. Environment adaptations | Program  
Control  
Waiting-list | Primary  
(1) **Visual reading ability**  
• By the Veterans Affairs Low Vision Visual Functioning Questionnaire (VA LV VFQ–48)\(^1\); interviewer administered  
Secondary  
Changes in other visual ability domains in the subsets of items in the same questionnaire:  
(2) **Mobility**  
(3) **Visual information processing**  
(4) **Visual motor skills**  
(5) **Overall visual ability** | At 4th month follow-up (short-term) | Primary  
(1) **Visual reading ability**: 2.43, ES 2.51, CI 2.07 to 2.77, \(p < .001\)  
Secondary  
(2) Mobility: 0.84, ES 1.14, CI 0.58 to 1.10, \(p < .001\)  
(3) Visual information processing: 1.38, ES 2.03, CI 1.15 to 1.62, \(p < .001\)  
(4) Visual motor skills: 1.51, ES 1.82, CI 1.22 to 1.80, \(p < .001\)  
(5) Overall visual ability: 1.63, ES 2.51, CI 1.40 to 1.86, \(p < .001\) |

* Data associated with significantly favorable result(s) are in **bolded** letters.

\(^1\) VA LV VFQ-48: assessed the ability in performing vision-dependent activities in 4 domains (reading, mobility, visual information processing, visual-guided motor behavior), in 48 items.
# Appendix B

## CASP Appraisal Tool for Randomized Controlled Trials

*(Public Health Resources Unit, National Health Service, 2010)*

### A/ Are the results of the trial valid?

#### Screening Questions

<table>
<thead>
<tr>
<th>Question</th>
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<th>Can't tell</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Did the trial address a clearly focused issue?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>An issue can be 'focused' in terms of</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- the population studied</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- the intervention given</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- the comparator given</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- the outcomes considered</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2. Was the assignment of patients to treatments randomized?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>3. Were all of the patients who entered the trial properly accounted for at its conclusion</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- was follow up complete?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- were patients analysed in the groups to which they were randomised?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

#### Detailed Questions

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Can't tell</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>4. Were patients, health workers and study personnel ‘blind’ to treatment?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- were the patients</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- were the health workers</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>- were the study personnel</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>5. Were the groups similar at the start of the trial?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>In terms of other factors that might effect the outcome such as age, sex, social class</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>6. Aside from the experimental intervention, were the groups treated equally?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### B/ What are the results?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>Can't tell</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>7. How large was the treatment effect?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>8. How precise was the estimate of the treatment effect?</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>What are its confidence limits?</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### C/ Will the results help locally?

<table>
<thead>
<tr>
<th>Question</th>
<th>Yes</th>
<th>No</th>
</tr>
</thead>
<tbody>
<tr>
<td>9. Can the results be applied to the local population?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Do you think that the patients covered by the trial are similar enough to your population?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>10. Were all clinically important outcomes considered?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>If not, does this affect the decision?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>11. Are the benefits worth the harms and costs?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>This is unlikely to be addressed by the trial. But what do you think?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Appendix C

RATING SCHEMES OF SIGN – STRENGTH OF EVIDENCE

METHODOLOGICAL QUALITY CODING SYSTEM
(Scottish Intercollegiate Guidelines Network, 2011)

| ++ | All or most of the criteria have been fulfilled. Where they have not been fulfilled the conclusions of the study or review are thought very unlikely to alter. |
| +  | Some of the criteria have been fulfilled. Those criteria that have not been fulfilled or not adequately described are thought unlikely to alter the conclusions. |
| -  | Few or no criteria fulfilled. The conclusions of the study are thought likely or very likely to alter. |

KEY TO EVIDENCE STATEMENTS
(Scottish Intercollegiate Guidelines Network, 2011)

| 1++ | High quality meta-analyses, systematic reviews of RCTs, or RCTs with a very low risk of bias |
| 1+  | Well-conducted meta-analyses, systematic reviews, or RCTs with a low risk of bias |
| 1-  | Meta-analyses, systematic reviews, or RCTs with a high risk of bias |
| 2++ | High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with a very low risk of confounding or bias and a high probability that the relationship is causal |
| 2+  | Well-conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal |
| 2-  | Case control or cohort studies with a high risk of confounding or bias and a significant risk that the relationship is not causal |
| 3   | Non-analytic studies, e.g. case reports, case series |
| 4   | Expert opinion |
# Appendix D

## HISTORY OF ELECTRONIC SEARCHES

**Ovid MEDLINE(R) (from 1948 to July 2011)**  
**Search date: 23.7.2011**

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<th>#</th>
<th>Searches</th>
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</tr>
</thead>
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<td>14934</td>
</tr>
<tr>
<td>2</td>
<td>macular dystrophy.mp.</td>
<td>771</td>
</tr>
<tr>
<td>3</td>
<td>retinal degeneration.mp. or exp Retinal Degeneration/</td>
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<tr>
<td>4</td>
<td>maculopathy.mp.</td>
<td>2256</td>
</tr>
<tr>
<td>5</td>
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<td>6</td>
<td>patient education.mp. or exp Patient Education as Topic/</td>
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</tr>
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<td>randomized controlled trials.mp. or exp Randomized Controlled Trial/</td>
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</tr>
<tr>
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<td>randomized controlled trial.mp.</td>
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<td>randomised controlled trial.mp.</td>
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<tr>
<td>12</td>
<td><strong>5 and 6 and 11</strong></td>
<td><strong>5 [3 full-text relevant]</strong></td>
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<td>13</td>
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<td>641</td>
</tr>
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<td>31</td>
<td><strong>5 and 11 and 30</strong></td>
<td><strong>120 [12 full-text relevant]</strong></td>
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Search terms used in Ovid MEDLINE(R)

(‘macular degeneration’ OR ‘macular dystrophy’ OR ‘retinal degeneration’ OR ‘maculopathy’) AND (‘randomized controlled trial’ OR ‘randomised controlled trial’) AND (‘patient education’ OR ‘emotional status’ OR ‘activities of daily living’ OR ‘functional ability’ OR ‘self-efficacy’ OR ‘teaching’ OR ‘skill training’ OR ‘behavioral change’ OR ‘knowledge’ OR ‘health knowledge’ OR ‘attitudes’ OR ‘practice’ OR ‘non-drug’ OR ‘non-pharmacological’ OR ‘program’ OR ‘intervention’ OR ‘intervention studies’)

Search results in Ovid MEDLINE(R)

- Possible studies retrieved: 202
- Full-text relevant studies before accounting for duplicates within this database: 23
- Full-text relevant studies after accounting for duplicates within this database: 7
### Searches

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<tr>
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<td>28 and 29</td>
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Search terms used in CINAHL Plus

(‘macular dystrophy’ OR ‘maculopathy’ OR ‘retinal degeneration’ OR ‘macular degeneration’) AND (‘patient education’ OR ‘program*’ OR ‘intervention’ OR ‘non-pharmacological’ OR ‘non-drug’ OR ‘teaching’ OR ‘skill* training*’ OR ‘emotional status’ OR ‘activit* of daily living*’ OR ‘functional abilit*’ OR ‘functional status’ OR ‘self-efficacy’ OR ‘behavioral change*’ OR ‘behavioral change’ OR ‘behavioral changes’ OR ‘behavioural changes’ OR ‘behavioural change’ OR ‘knowledge’ OR ‘knowledges’ OR ‘health’ OR ‘attitude*’ OR ‘practice’)

Search results in CINAHL Plus

- Possible studies retrieved: 3
- Full-text relevant studies before accounting for duplicates within this database: 3
- Full-text relevant studies after accounting for duplicates within this database: 1
EMBASE (classic +from 1947 to September 2011)  Search date: 17.9.2011

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<td>30</td>
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<td>31</td>
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<td>33</td>
<td>limit 29 to (human and aged &lt;65+ years&gt;)</td>
<td>68 [4 full-text relevant]</td>
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Search terms used in EMBASE

(‘macular degeneration’ OR ‘macular dystrophy’ OR ‘maculopathy’ OR ‘retina maculopathy’ OR ‘retinal degeneration’ OR ‘retina degeneration’) AND (‘randomized controlled trial’ OR ‘randomized controlled trials’) AND (‘patient education’ OR ‘program*’ OR ‘intervention’ OR ‘non-pharmacological’ OR ‘non-drug’ OR ‘teaching’ OR ‘skill* training*’ OR ‘emotional status’ OR ‘self-efficacy’ OR ‘self concept’ OR ‘daily life activity’ OR ‘activity of daily living’ OR ‘activities of daily living’ OR ‘functional abilit*’ OR ‘behavioral chang*’ OR ‘knowledge’ OR ‘health’ OR ‘attitude’ OR ‘practice’)

Search results in EMBASE

- Possible studies retrieved: 130
- Full-text relevant studies before accounting for duplicates within this database: 7
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# QUALITY APPRAISAL RESULTS

## APPRAISAL TABLE 1 of 5

<table>
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<tr>
<th>Critical Appraisal Skills Programme (CASP) Appraisal Tool for RCT (PHRU, NHS, 2010)</th>
<th>1</th>
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<td><strong>Brody et al., 2002</strong> (follow-up study of Brody et al., 2002)</td>
<td><strong>Brody et al., 2005</strong></td>
<td><strong>Brody et al., 2002</strong></td>
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<td>Q1. Did the trial address a clearly focused issue?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q2. Was the assignment of patients to treatments randomized?</td>
<td>Yes (computer)</td>
<td>Yes (computer)</td>
</tr>
<tr>
<td>Q3. Were all of the patients who entered the trial properly accounted for at its conclusion?</td>
<td>No (but reported no diff. in demographic characteristics between those completed 6-week follow-up &amp; those who declined)</td>
<td>No (but reported no diff. in demographic characteristics between those completed 6-mon follow-up &amp; those who declined)</td>
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<tr>
<td>Q4. Were patients, health workers and study personnel ‘blind’ to treatment?</td>
<td>Yes (sealed envelop, signed by 2, opened with 2 witnesses, key in double-sealed envelope, recorded with password-protected database)</td>
<td>Yes (sealed envelop, signed by 2, opened with 2 witnesses, key in double-sealed envelope, recorded with password-protected database)</td>
</tr>
<tr>
<td>Q5. Were the groups similar at the start of the trial?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q6. Aside from the experimental intervention, were the groups treated equally?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q7. How large was the treatment effect? What outcomes are measured?</td>
<td>Effect size between groups not reported; significantly improved emotional distress/vision-related functioning/self-efficacy</td>
<td>Effect size between groups not reported; significantly improved emotional distress/vision-related functioning/self-efficacy/incidence of depression: RR 0.49</td>
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<tr>
<td>Q8. How precise was the estimate of the treatment effect? What are its confidence limits?</td>
<td>P-level=0.05 &amp; 95%CI limits</td>
<td>P-level=0.05 &amp; 95%CI limits</td>
</tr>
<tr>
<td>Q9. Can the results be applied to the local population?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q10. Were all clinically important outcomes considered?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q11. Are the benefits worth the harms and costs? <em>This is unlikely to be addressed by the trial. But what do you think?</em></td>
<td>Yes</td>
<td>Yes</td>
</tr>
</tbody>
</table>

**Level of Evidence**

| 1++ | RCT with a very low risk of bias | 1++ | RCT with a very low risk of bias |
## Critical Appraisal Skills Programme (CASP)

### Appraisal Tool for RCT (PHRU, NHS, 2010)

<table>
<thead>
<tr>
<th>Question</th>
<th>Brody et al., 2006 (follow up study of Brody et al., 2002)</th>
<th>Dahlin et al., 2002</th>
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<tbody>
<tr>
<td>Q1. Did the trial address a clearly focused issue?</td>
<td>Yes</td>
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<td>Yes (computer)</td>
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<td>No (but reported no diff. in demographic characteristics between those completed 6-mon follow-up &amp; those who declined)</td>
<td>No</td>
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<tr>
<td>Q4. Were patients, health workers and study personnel ‘blind’ to treatment?</td>
<td>Yes (sealed envelop, signed by 2, opened with 2 witnesses, key in double-sealed envelope, recorded with password-protected database)</td>
<td>No (outcomes were self-reported; evaluators not involved in the program, not likely lead to observer bias)</td>
</tr>
<tr>
<td>Q5. Were the groups similar at the start of the trial?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q6. Aside from the experimental intervention, were the groups treated equally?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q7. How large was the treatment effect? What outcomes are measured?</td>
<td>Effect size between groups not reported; significantly improved depression symptom scores/ self-efficacy</td>
<td>Effect size between groups not reported; Sig. improvement in perceived security in several daily activities</td>
</tr>
<tr>
<td>Q8. How precise was the estimate of the treatment effect? What are its confidence limits?</td>
<td>P-level=0.05</td>
<td>P-level=0.05 &amp; 95% CI limits</td>
</tr>
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<td>Q9. Can the results be applied to the local population?</td>
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<td>Yes</td>
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### Level of Evidence

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<td><strong>Q1. Did the trial address a clearly focused issue?</strong></td>
<td>Yes</td>
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<tr>
<td><strong>Q2. Was the assignment of patients to treatments randomized?</strong></td>
<td>Yes</td>
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<tr>
<td><strong>Q3. Were all of the patients who entered the trial properly accounted for at its conclusion?</strong></td>
<td>No (but reported no diff. in baseline characteristics between those completed 28-mon follow-up &amp; those who declined)</td>
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<tr>
<td><strong>Q4. Were patients, health workers and study personnel ‘blind’ to treatment?</strong></td>
<td>No (outcomes were self-reported; data collector not involved in the program, not likely lead to observer bias)</td>
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<tr>
<td><strong>Q5. Were the groups similar at the start of the trial?</strong></td>
<td>Yes</td>
</tr>
<tr>
<td><strong>Q6. Aside from the experimental intervention, were the groups treated equally?</strong></td>
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<td>Effect size between groups not reported; Sig. improvement in perceived security in several daily activities</td>
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<td><strong>Q8. How precise was the estimate of the treatment effect? What are its confidence limits?</strong></td>
<td>P-level=0.05 &amp; 95%CI limits</td>
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<td><strong>Q9. Can the results be applied to the local population?</strong></td>
<td>Yes</td>
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<td>Yes</td>
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<td><strong>Q11. Are the benefits worth the harms and costs? This is unlikely to be addressed by the trial. But what do you think?</strong></td>
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**Level of Evidence**

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### Critical Appraisal Skills Programme (CASP)

**Appraisal Tool for RCT**  
*(PHRU, NHS, 2010)*

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<tr>
<td>Q2. Was the assignment of patients to treatments randomized?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q3. Were all of the patients who entered the trial properly accounted for at its conclusion</td>
<td>No (but reported no diff. in baseline characteristics between those completed 28-mon follow-up &amp; those who declined)</td>
<td>No (reported no diff. in baseline characteristics between the subjects who declined &amp; those retained at times of measurements)</td>
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<td>Q4. Were patients, health workers and study personnel ‘blind’ to treatment?</td>
<td>No</td>
<td>Yes (personnel masked to treatment assignment completed central data collection, measurement &amp; data entry)</td>
</tr>
<tr>
<td>Q5. Were the groups similar at the start of the trial?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q6. Aside from the experimental intervention, were the groups treated equally?</td>
<td>Yes</td>
<td>Yes</td>
</tr>
<tr>
<td>Q7. How large was the treatment effect? What outcomes are measured?</td>
<td>Effect size between groups not reported; Self-reported health problem/ vision functioning/ general health</td>
<td>OR 0.39 for incidence of clinical depression (2-month); OR 0.48 for rate of relinquishing value activities reduced (2-month)</td>
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<tr>
<td>Q8. How precise was the estimate of the treatment effect? What are its confidence limits?</td>
<td>P-level=0.05 &amp; 95%CI limits</td>
<td>P-level=0.05 &amp; 95%CI limits</td>
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<td>Q9. Can the results be applied to the local population?</td>
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<tr>
<td>Q11. Are the benefits worth the harms and costs?</td>
<td>Yes</td>
<td>Yes</td>
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*This is unlikely to be addressed by the trial. But what do you think?*

<table>
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<th>1++</th>
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<td>RCT with a low risk of bias</td>
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## Critical Appraisal Skills Programme (CASP) Appraisal Tool for RCT (PHRU, NHS, 2010)

| Q1. Did the trial address a clearly focused issue? | Yes |
| Q2. Was the assignment of patients to treatments randomized? | Yes (computer) |
| Q3. Were all of the patients who entered the trial properly accounted for at its conclusion? | Yes |
| Q4. Were patients, health workers and study personnel ‘blind’ to treatment? | Yes (masked by telephone interview; disclosure tracked) |
| Q5. Were the groups similar at the start of the trial? | Yes |
| Q6. Aside from the experimental intervention, were the groups treated equally? | Yes |
| Q7. How large was the treatment effect? What outcomes are measured? | Overall visual function: ES 2.51; (All subsets of visual function: ES 2.51 for visual reading ability; ES 1.14 for mobility; ES 2.03 for visual information processing & ES 1.82 for visual motor skills) |
| Q8. How precise was the estimate of the treatment effect? What are its confidence limits? | P-level=0.05 & 95% CI limits |
| Q9. Can the results be applied to the local population? | Yes |
| Q10. Were all clinically important outcomes considered? | Yes |
| Q11 Are the benefits worth the harms and costs? | Yes |

*This is unlikely to be addressed by the trial. But what do you think?*

### Level of Evidence

**1++**

RCT with a very low risk of bias
### THE SELF-EFFICACY QUESTIONNAIRE

#### AGE-RELATED MACULAR DEGENERATION SELF-EFFICACY QUESTIONNAIRE*

**AMD-SEQ**

I will read to you a series of questions which will ask how certain you are under different circumstances. The answers you may select range from 1 to 100 with one being VERY UNCERTAIN and one hundred being VERY CERTAIN.

1. How certain are you that you know what macular degeneration is?
   *From 1 to 100*
   
   
2. How certain are you that you can explain what is known about macular degeneration to a relative or friend so they can better understand your condition?

3. If you cannot see the face of a friend clearly, how certain are you that you can comfortably ask for the friend's name?

4. How certain are you that you can maintain a simple exercise program which is tailored to your needs?

5. How certain are you that you can comfortably communicate questions or concerns about your macular degeneration to your doctor?

6. How certain are you that you can find out where to get more information about services for people with low vision?
7. How certain are you that you can find transportation to an appointment or event whenever you need to?

8. How certain do you feel that you can call someone on the phone for any reason? (or can you use the telephone?)

<table>
<thead>
<tr>
<th>Self-Efficacy</th>
</tr>
</thead>
<tbody>
<tr>
<td>AMDR</td>
</tr>
</tbody>
</table>

9. How certain are you that you know about most of the different types of low-vision aids that are available?

10. How certain are you that you can comfortably leave your house on your own?

11. How certain are you that you can get involved in some new activities such as cultural events or recreation, for example?

12. How certain are you that you can maintain contact with persons with Macular Degeneration who share similar interests as yourself?

13. How certain are you that you can feel comfortable participating in a social gathering with a few friends? (How many people?)

© Division of Community Ophthalmology, Department of Ophthalmology, Shiley Eye Center, University of California San Diego
TIPS FOR AMD PATIENT TO ENHANCE CAPACITY
AND MAINTAIN ACTIVE LIVING

Basic tips include:

Improve Lighting:
Use direct lighting from behind. Make sure stairs, bathrooms, kitchens and other areas of activity are well lit.

Increase Contrast:
Pour drinks/coffee into white cups and put white plates on dark place mats. Use a felt-tip pen, not a ball point. Have a dark chopping board and a light one. Chop dark items (e.g., meat) on the light board and light items (e.g., onion) on the dark board.

Control Glare:
Wear sunglass fit-overs or clip-ons and a visor outside. Cover shiny surfaces with a cloth.

Enlarge:
Get large-size cheques from your bank. Use the accessibility features on
computers or purchase enlargement software.

**Label:**

Use bright, contrasting labels, dark felt pens and raised tactile paint on dials, remotes and domestic appliances.

**Orientation and Mobility Tips**

**Around the home**

Place a contrasting and non-slip strip on the front edge of steps making them easier to see. This can reduce the risk of falls, particularly if the strip is right on the edge of the tread and about 50mm or 2 inches wide.

Place a chair near the back door so when entering from outside there is somewhere to wait until the eyes adjust to the changed lighting conditions.

Keep cupboard doors and drawers closed at all times, and put away items in the same place each time.

Mark door handles and steps with reflective tape. Be aware of stairs, steps, and changes in levels.

**In the Kitchen**

Ensure that the kitchen is well lit.

If possible, use dishes and cookware in a colour that contrasts with the countertop.
Replace electrical outlet covers in a colour that contrasts with the wall.

Outline counter edges and electrical outlets with wide tape of a contrasting colour.

If the stove surface is a light colour, consider replacing stainless steel pots with dark-coloured ones.

Use light-coloured dishes on a dark tablecloth, or vice versa.

Mark frequently used settings on the oven or other dials with adhesive tactile.

Remove small throw rugs from the kitchen. They are not easily seen and may be a tripping hazard.

Keep cupboard doors and drawers closed at all times, and put away items in same place each time.

Use the clock method to identify where certain foods are located on a plate for a meal. For example, “The rice is at three o’clock and the vegetables are at seven o’clock”.

**In the Bathroom**

Use illuminated and magnifying mirrors in the bathroom.

Use coloured toothpaste so it shows more on the white bristles of a toothbrush.

Put the toothpaste on your finger and then apply it to the toothbrush.

Use towels that contrast in colour with the bathroom.

Use a rubber-backed mat in the tub.
Float a brightly coloured sponge while running the bath water, as the sponge will indicate how high the water has risen.

Label current medication with a thick black letter on each bottle. Use a large print pill box.

Pick up the bath mat after each use and fold it over the edge of the tub to prevent tripping.

**Travelling Independently**

The support and guidance of a mobility specialist can assist in the process of independent travel. Some people who are blind or who have low vision will be more open to the idea of independent travel than others. For those who need a period of adjustment, support from a carer in organising travel can be an excellent and practical option.

**When out and about**

Choose well lit routes to travel. Find alternate routes around dangerous intersections and construction areas. Use curbing or line up streetlights as a guide.

Be aware of contrast on sidewalks. Wherever possible take the elevator to avoid stairs.

If available, use hand railings when using stairs.
Try to cross the road where you can see and be seen.

Where possible, cross at the traffic lights.

Be aware of cars pulling into driveways.

Identify coins by touch and fold paper money. Also try separating the paper money into different sections of the wallet.

Take a moment to let the eyes adjust when switching from a bright environment to a dimly lit one.

Carry a magnifier and/or penlight to read labels, price tags, elevator buttons, or directions.

Use a mini tape recorder to make a shopping list, instead of struggling with a handwritten list.

**Using public transport**

Plan ahead and allow ample time to travel.

Get organised before the bus arrives, so that money and bus passes are easily accessible.

Ask the driver to wait until you are seated before they start driving.

Tell the bus driver in advance which stop you require.

Sit at the front of the bus and near the door.

**Lifestyles and Hobbies**
Being accompanied by a friend or companion, who can make the initial introductions.

Activities such as reading or playing chess continue with a little patience and adjustment.

Walking with a friend instead of alone and using a local walking track or local oval for longer distance exercise can also be an option.

Stationary bikes and other seated equipment in elderly activities centers are also an excellent way of staying active.


Appendix H

RATING SCHEME OF SIGN - KEY TO GRADES OF RECOMMENDATIONS
(Scottish Intercollegiate Guidelines Network, 2011)

A

At least one meta-analysis, systematic review, or RCT rated as 1++, and directly applicable to the target population; or

A body of evidence consisting principally of studies rated as 1+, directly applicable to the target population, and demonstrating overall consistency of results

B

A body of evidence including studies rated as 2++, directly applicable to the target population, and demonstrating overall consistency of results; or

Extrapolated evidence from studies rated as 1++ or 1+

C

A body of evidence including studies rated as 2+, directly applicable to the target population and demonstrating overall consistency of results; or

Extrapolated evidence from studies rated as 2+

D

Evidence level 3 or 4; or

Extrapolated evidence from studies rated as 2+

Good practice points

Recommended best practice based on the clinical experience of the guideline development group
Appendix I

CLIENT SATISFACTION QUESTIONNAIRE

Self-management Education Programme (SEP) for Older Adults with Age-related Macular Degeneration (AMD)

Client Satisfaction Questionnaire
(nurse-administered)

Thank you for your participation in the self-management education programme. We have composed the following questionnaire to evaluate the program in order to facilitate our future improvements. The answers you may express include ‘strongly agree’, ‘agree’, ‘disagree’, and ‘strongly disagree’. Please tell me the one expression which you think the most appropriate to you. We also invite open comments. (The nurse may choose either to complete an individual questionnaire for each of the participants or to use a voting method and write down the respective number of votes in the brackets provided)

Date:_______________________
Name of EHC:_________________ Name of participant: __________________

Part A: To the programme content –

1. Do you find the visual aids in this programme tailored to your visual needs?
   □ 4Strongly agree (  ) □ 3Agree (  ) □ 2Disagree (  ) □ 1Strongly disagree (  )

2. Do you feel the programme organized and content understandable?
   □ 4Strongly agree (  ) □ 3Agree (  ) □ 2Disagree (  ) □ 1Strongly disagree (  )

3. Do you find the topics adequate to meet your daily living needs regarding AMD?
   □ 4Strongly agree (  ) □ 3Agree (  ) □ 2Disagree (  ) □ 1Strongly disagree (  )

4. Which session(s) or topic(s) do you like most?

5. Any topics that you feel necessary to be added to this programme?

Part B: To the programme arrangement –

1. Do you feel the length of the programme is appropriate?
   □ 4Strongly agree (  ) □ 3Agree (  ) □ 2Disagree (  ) □ 1Strongly disagree (  )

2. Do you feel the assignment workload is appropriate?
   □ 4Strongly agree (  ) □ 3Agree (  ) □ 2Disagree (  ) □ 1Strongly disagree (  )

3. Do you feel the home visit by the occupational therapist helpful?
Pat C: To your overall perception—

1. Do you feel your knowledge regarding AMD enriched after finishing this programme?
   □ 4 Strongly agree ( ) □ 3 Agree ( ) □ 2 Disagree ( ) □ 1 Strongly disagree ( )

2. Do you feel this programme helpful in reducing your emotional distress caused by AMD?
   □ 4 Strongly agree ( ) □ 3 Agree ( ) □ 2 Disagree ( ) □ 1 Strongly disagree ( )

3. Do you feel more confident in coping with AMD after this programme?
   □ 4 Strongly agree ( ) □ 3 Agree ( ) □ 2 Disagree ( ) □ 1 Strongly disagree ( )

4. Do you feel your self-help ability regarding AMD vision problems increased after completing this programme?
   □ 4 Strongly agree ( ) □ 3 Agree ( ) □ 2 Disagree ( ) □ 1 Strongly disagree ( )

5. What else do you want to say for this programme?

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~Thank You~
Appendix J

EVALUATION QUESTIONNAIRE FOR STAFF

Self-management Education Programme (SEP) for Older Adults with Age-related Macular Degeneration (AMD)

Evaluation Questionnaire
(for programme implemented staff)

Thank you for your participation in the self-management education programme. We have composed the following questionnaire to evaluate the program in order to facilitate our future improvements.

Date: ____________________
Name of EHC: ____________________ Name of Staff: ____________________

Please tick the boxes and write your comments where appropriate.

Part A: Over the implementation of the programme –
1. Do you feel the workload of the programme is appropriate?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
2. Do you feel a satisfaction on this program?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
3. Do you feel helpful to your nursing role from the additional skills of this program?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
4. Do you feel to gain the knowledge from this program?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
5. Do you feel confident in the implementation of the programme?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree

Part B: Over the programme content –
1. Do you find the content adequate to meet the programme goal?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
2. Do you find the programme content comprehensive?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
3. Do you find the programme content clear for delivery?
   □ 4Strongly agree □ 3Agree □ 2Disagree □ 1Strongly disagree
4. What are the useful parts of the programme protocol and the programme content?
5. Which parts of the programme protocol or content you find difficult and need further elaboration?

__________________________________________________________________

6. The ways in which the programme could be improved:

__________________________________________________________________

Part C: The training session
1. Do you feel the training session useful?
   □ 4 Strongly agree   □ 3 Agree   □ 2 Disagree   □ 1 Strongly disagree

2. What else do you want to say regarding this programme?

__________________________________________________________________

~Thank You~