Chapter 4:

Why visually impaired older adults often do not receive mental health services: the patient's perspective

Abstract

Objectives
Visually impaired older adults often experience mental health problems, however, they tend to underutilise mental health services. The present study aims to determine the utilisation of, the perceived need for, and barriers to use mental health services in this population.

Methods
A cross-sectional study in 871 visually impaired older adults (mean age 73 years) from outpatient low vision rehabilitation organisations was conducted. A multinomial logistic regression analysis was performed to assess potential related factors to perceived need for mental health services, based on Andersen's behavioural model.

Results
About 35% of the population had subthreshold depression and/or anxiety and 13% had a depressive and/or anxiety disorder according to the DSM-IV. Almost 34% of the participants with an actual disorder did not receive mental health services, even though 57% perceived to be in need of these services. Participants who had more severe depression and/or anxiety, comorbid depression and anxiety, no history of major depressive disorder, a lower perceived health status and a younger age were more likely to be in need of mental health services. Barriers to receive these services were lack of knowledge and self-reliance.

Conclusions
The results support the implementation of screening and monitoring procedures and patient empowerment within low vision rehabilitation services.

Introduction

An estimated 285 million people worldwide are visually impaired, of whom 65% are 50 years or older.[1] Vision loss is associated with limitations in daily life activities, reduced health-related quality of life, and increased depressive and anxiety symptoms.[2-5] About one-third of visually impaired older adults experience clinically significant symptoms of depression and/or anxiety (called subthreshold depression and/or anxiety),[2-9] which is at least twice as high as the prevalence in the general older population.[10-12] Subthreshold depression has the potential to progress to major depressive disorder.[13-17] About 7% of older adults with visual impairment have a major depressive disorder,[2,18] which is substantially higher than the community prevalence in older adults (mean prevalence 1.8%).[10] Depression and anxiety have been considered serious medical conditions as they may aggravate disability caused by visual impairment, and decrease health-related quality of life.[19-22]

However, depression and anxiety often remain undetected and untreated in visually impaired older adults.[23-25] This may be due to the difficulty of distinguishing depression from normal grief associated with loss of vision and the infrequent use of screening tools.[25] The focus of both professionals and patients is often on physical symptoms and less on psychological issues.[23-25] Moreover, patients often do not perceive a need for professional mental health services.[26-32]

Andersen's Behavioural Model is one of the most widely used frameworks to determine healthcare use.[27] The model distinguishes three factors that determine utilisation and perceived need for mental health services from the patient's perspective: 1) predisposing factors, 2) enabling factors and 3) clinical need factors. Predisposing factors represent biological imperatives for the need of health services, such as age, gender and education. Enabling factors are necessary for utilisation to actually take place, such as income level and insurance coverage. Clinical need factors represent illness variables, such as perceived health status and severity of depression and anxiety.

Insight in the perceived need for and barriers to use mental health services in older adults with visual impairment is limited. Therefore, extensive research, based on a widely used framework as Andersen's Behavioural Model, is warranted. This may offer important indications to direct an inherently vulnerable population to the services they need, which can improve their autonomy, participation, psychological wellbeing and quality of life. In this study: 1) the utilisation of mental health services, 2) the perceived need for mental health services, 3) factors associated with perceived need for mental health services, and 4) barriers for not receiving (sufficient) mental health services are investigated in visually impaired older adults (aged ≥50 years).

We hypothesize, mainly based on previous research,[26,32] that the predisposing factors: gender, age, country of birth, education and living situation, the enabling factor: income level, and the clinical need factors: perceived health status, severity of depression and/or anxiety, comorbid depression and anxiety, history of major depressive disorder, visual acuity, cause of visual impairment, time of onset of visual loss and somatic comorbidity, influence perceived need for mental health services in visually impaired older adults.

Methods

Design and Sample
Cross-sectional data in 871 visually impaired patients from outpatient low vision rehabilitation organisations in the Netherlands and Belgium were collected from September 2012 to July 2013 as part of the baseline measurement of a randomised controlled trial (trial registration: http://www.trialregister.nl, identifier: NTR3296).[33] A total of 3,000 patients of 50 years and older were addressed to take part in the study. Eligibility criteria for low vision rehabilitation organisations

are described in the Dutch guideline 'Vision disorders, rehabilitation and referral',[34] stating that all patients should have a decimal visual acuity of ≤0.3 and/or a visual field of ≤30 degrees around the central point of fixation and/or an evident help request for which therapeutic options in regular ophthalmic practice are not sufficient. Of the 3,000 addressed patients, 914 gave their written consent to participate (response rate 30.5%) and were screened for eligibility. Patients were eligible for the present study if they had sufficient knowledge of the Dutch language, had no severely impaired cognitive functioning (as measured with the six-item screener),[35]and answered at least one question on the main outcome measure (i.e. the Perceived Need for Care Questionnaire, PNCQ).

Measures

Perceived need for mental health services
In order to measure perceived need for mental health services and the utilisation of these services, the PNCQ was used. This questionnaire was designed for the Australian National Survey of Mental Health and Well-being and showed acceptable reliability, validity and feasibility.[36] In the present study the translated Dutch version of the PNCQ from the Netherlands Study of Depression and Anxiety (NESDA) was used.[37] Descriptive information of five different types of mental health services was distinguished: 1) information about mental illnesses and treatment possibilities; 2) practical support, e.g. vision specific tools or domestic help; 3) skills training; 4) counselling/therapy; and 5) medication.[36] In concurrence with a comparable study in a Dutch general older population, a sixth category: 'referral to a mental health services specialist' was added.[31] Respondents were asked if they received some type of care in the past six months, if this type of care was needed, and if it was sufficient. Additionally, participants with an unmet need for mental health services could indicate one of nine possible barriers for not receiving (sufficient) mental health services: 1) self-reliance; 2) pessimism; 3) financial situation; 4) lack of knowledge; 5) stigma; 6) non-response; 7) being on a waiting list; 8) already in treatment, or 9) alternative help was provided.[36]

Visual acuity
Decimal visual acuity was retrieved from patient files at the low vision rehabilitation organisations and supplemented with answers that visually impaired older adults themselves gave. These were converted into logMAR visual acuity in the best eye, with a visual acuity of 0.00-0.29 indicating normal visual acuity, 0.30-0.51 mild vision loss and 0.52-2.00 indicating low vision or blindness.

Somatic comorbidity
Somatic comorbidity was assessed based on: osteoarthritis and rheumatoid arthritis; asthma or chronic obstructive pulmonary disease; cancer; peripheral arterial disease; diabetes mellitus; cardiac disease; cerebrovascular accident or stroke; and other chronic health disorders.

Depression and anxiety
Depression and anxiety symptoms were measured with the widely used Centre for Epidemiologic Studies Depression scale (CES-D). The CES-D consists of 20 items with four response categories, with scores ranging from 0-60, with a score of ≥16 indicating subthreshold depression. It is considered a valid and reliable instrument in Dutch older adult populations for measuring depressive and anxiety symptomatology.[38-40] The Hospital Anxiety and Depression Scale - Anxiety (HADS-A) was used in the present study to measure anxiety. HADS-A is considered a valid and reliable instrument to use in Dutch older adult populations. It has seven items with four response categories and scores ranging from 0-21, with a score of ≥ 8 indicating subthreshold anxiety.[41-43]

To distinguish participants with a DSM-IV depressive disorder (major depressive or dysthymic disorder) and/or anxiety disorder (panic disorder (with or without agoraphobia), agoraphobia (without a history of panic disorder), social phobia and/or generalized anxiety disorder) the Dutch version of the Mini International Neuropsychiatric Interview (MINI Plus 5.0.0 developed in

clinician–rated format) was used. The MINI has proven to be a valid instrument to use in medical telephone screening and an appropriate standardised tool to diagnose DSM-IV depressive and anxiety disorders in Dutch clinical practice.[44,45]

Severity of depression and anxiety was based on: 1) having no depression and anxiety (CES-D score of <16 and HADS-A score of <8); 2) having subthreshold depression and/or anxiety (CES-D score of ≥16 and/or HADS-A score of ≥8); or 3) having a depressive and/or anxiety disorder (based on the MINI).

Perceived health status
Perceived health status was measured using the Dutch Euroqol-5 Dimensions (EQ5D), which is considered a valid and reliable instrument. The EQ5D consists of five dimensions of functional impairment: mobility, self-care, usual activities, pain/discomfort and anxiety/depression. Scores range from 0 (which corresponds to death) to 1 (which corresponds to full health).[46]

Statistical analysis
First, (similar to a study in community subjects)[30] the outcome variable perceived need for mental health services was categorised into three groups; 1) no need of mental health services; 2) in need of mental health services, which indicated that a person's need was not or only partially met; and 3) met need of mental health services, which indicated that the need for mental health services was fully met. To measure perceived health status, the scores of the EQ5D were calculated according to validated Dutch standard values.[46] Second, to determine potential factors related to perceived need for mental health services a multinomial logistic regression analysis was performed, with the 'in need' group as reference group. The assumption of absence of multicollinearity between the different covariates was tested. The best fitting model was determined based on a backwards stepwise procedure. Data analysis was performed using SPSS for Windows version 20 (SPSS IBM, New York, USA).

Results

Patient characteristics, service utilisation and perceived need
No significant difference was found between responders and non-responders in gender; however, non-responders were significantly older than responders (mean difference=4.6 years, *P*<0.001). The most common reasons for not participating in the study were: i) patients were physically or mentally not able to participate, and ii) it was too great a burden to participate. Participants were mainly female, had an average age of 73 years and almost all of them lived independently (Table 1). The most frequent cause of vision loss was macular degeneration and the median time of onset of visual loss was 8 years ago. About 35% suffered from subthreshold depression and/or anxiety and 13% had an actual disorder according to the DSM-IV. About 57% of the study population did not receive any form of mental health services. Practical support was the most frequently received form of help, followed by medication. Mental health services were mostly offered by a social worker, followed by a psychologist or psychiatrist.

TABLE 1. Characteristics of the study population (*n*=871)

Patient characteristics		
Female gender (*n*, (%))		527 (61%)
Age in years, range [50-98] (mean (*SD*))		73.3 (12.1)
Country of birth (*n*, (%))	Dutch	766 (88%)
	Belgian/ Other	105 (12%)
Education (years), range [0-16] (mean (*SD*))		10.2 (3.5)
Income level (*n*, (%))	Usually enough money	426 (49%)
	Just enough money	363 (42%)
	Not enough money	65 (8%)
Living situation (*n*, (%))	Independent	818 (94%)
	Care home/ Other	53 (6%)
Cause of visual impairment (*n*, (%))	Macular degeneration	399 (46%)
	Glaucoma	137 (16%)
	Cataract	122 (14%)
	Cerebral haemorrhage	49 (6%)
	Diabetic retinopathy	33 (4%)
	Other	131 (15%)
Time of onset visual loss in years, (median [25-75% percentiles])		8 [3-20]
Visual acuity best eye logMAR (*n*, (%))	Normal visual acuity	106 (12%)
	Mild vision loss	159 (18%)
	Low vision or blindness	550 (63%)
Somatic comorbidity, range [0-7] (mean (*SD*))		1.0 (1.1)
No symptoms of depression/anxiety (*n*, (%))		515 (59%)
Subthreshold depression and/or anxiety (*n*, (%))		308 (35%)
Depressive and/or anxiety disorder (*n*, (%))		117 (13%)
Depressive and anxiety disorder (*n*, (%))		33 (4%)
History of major depressive disorder (*n*, (%))		127 (15%)
Types of mental health services received (*n*, (%))	Information	92 (11%)
	Practical support	228 (26%)
	Skills training	21 (2%)
	Counselling / Therapy	96 (11%)
	Medication	102 (12%)
	Referral to specialist	38 (4%)
	No services received	499 (57%)
Clinicians/ care providers (*n*, (%))	Social worker	178 (20%)
	Psychologist or psychiatrist	87 (10%)
	Outpatient or hospital treatment	7 (1%)
	Other	77 (9%)

Means and standard deviations (*SD*) are reported for continuous variables, median and 25-75% percentiles are provided when the variable has an asymmetric distribution.

Table 2 shows that about 53% of the respondents with subthreshold depression and/or anxiety and 34% of the respondents with a depressive and/or anxiety disorder did not receive any form of mental health services in the past six months, indicating that as the severity of depression and anxiety increased, participants more often received mental health services. In addition, as symptoms of depression and anxiety increased, participants more often expressed a need for professional mental health services; 57% of the participants with a depressive and/or anxiety disorder reported to be in need of mental health services compared to 29% of the participants with subthreshold symptoms.

TABLE 2. Severity of depression and/or anxiety in relation to received and perceived need for mental health services

	Received mental health services			Need for mental health services			
Depression/anxiety	No care	Some form of care	Total	No need	Met need	In need	Total
No symptoms (*n*, (%))	319 (64%)	182 (36%)	501	329 (66%)	116 (23%)	56 (11%)	501
Subthreshold symptoms (*n*, (%))	112 (53%)	98 (47%)	210	91 (43%)	58 (28%)	61 (29%)	210
Disorder (*n*, (%))	39 (34%)	75 (66%)	114	31 (27%)	18 (15%)	65 (57%)	114
Total (*n*, (%))	470 (57%)	355 (43%)	825	451 (55%)	192 (23%)	182 (22%)	825

Participants who were in need of mental health services expressed 394 different requests for help; often, they reported more than one type of request (Table 3). Participants were most often in need of practical support; skills training; information about mental illnesses and treatment possibilities and counselling/therapy. A need for medication and referral to a mental health services specialist were least often reported. Participants expressed different reasons for not receiving treatment (Table 4). Lack of knowledge was mentioned most often, followed by self-reliance, being on a waiting list, non-response, and already being under treatment.

TABLE 3. Requests for help in patients expressing a need for mental health services (*n*=182)

Types of requests	*n*	%
Practical support	89	23
Skills training	87	22
Information	85	22
Counselling/therapy	79	20
Referral to mental health services specialist	40	10
Medication	14	4
Total	394	100

TABLE 4. Perceived reasons for not receiving mental health services in patients expressing a need for mental health services (*n*=182)

Cited reason	n	%
Lack of knowledge ('I didn't know where to get (extra) help')	119	32
Self-reliance ('I rather solve it myself')	61	16
Waiting list ('I am on a waiting list')	52	14
Non-response ('I asked for it but didn't get it')	43	11
Already in treatment ('I am already in treatment')	39	10
Pessimism ('I thought this would not help')	21	6
Stigma ('I was afraid to ask for help; what would others think?')	16	4
Financial situation ('I did not have the money')	14	4
Alternative help ('I already received help in another form/capacity')	13	3
Total	**378**	**100**

Potential factors related to perceived need for mental health services

No plausible multicollinearity was found as the variance inflation factor (VIF) was less than three for all covariates in relation to the other covariates in the model. All the predisposing, enabling and clinical need factors were included in a multinomial logistic regression model (Table 5; full model). After conducting the backward stepwise procedure the *predisposing factor:* age and the *clinical need factors*: severity of depression and/or anxiety, comorbid depression and anxiety, history of major depressive disorder and perceived health status, proved to be significantly related to perceived need for mental health services (Table 5; end model). The final model was statistically significant, χ² (10, *n*=871) =172.6, *P*<.001 and explained 18.9% (Cox and Snell R square) to 21.8% (Nagelkerke R squared) of the variance in perceived need for mental health services.

The strongest factor related to perceived need for mental health services was severity of depression and/or anxiety. Compared to respondents with a depressive and/or anxiety disorder, respondents with subthreshold depression and/or anxiety and no symptoms were significantly more likely to have no need for mental health services than to be in need of these services (OR 1.92; 95% confidence interval (CI) 1.05 to 3.50, and OR 6.07; 95% CI 3.33 to 11.06, respectively) and were significantly more likely to have their needs met than to be in need of mental health services (OR 2.60; 95% CI 1.27 to 5.31, and OR 5.72; 95% CI 2.76 to 11.84, respectively). These results show that participants were more often in need of mental health services as the severity of depression and/or anxiety increased. In addition, participants with comorbid depression and anxiety were significantly more likely to be in need of mental health services than to have no needs for these services (OR 4.26; 95% CI 1.15 to 15.80). Participants with higher perceived health status were more likely to have no need for mental health services than to be in need of care (OR 3.94; 95% CI 1.74 to 8.94) and patients with a history of major depressive disorder were more likely to have met needs than to be in need of mental health services (OR 0.51; 95% CI 0.28 to 0.90). Furthermore, the model shows that as age increased participants were more likely to express no need and met needs for mental health services, than to be in need of care (OR 1.03; 95% CI 1.02 to 1.05, and OR 1.02; 95% CI 1.00 to 1.04, respectively), indicating that participants with a younger age were more likely to be in need of mental health services.

TABLE 5. Multinomial logistic regression: the effects of patient characteristics on perceived need for mental health services (MHS)

	Full model					End model					
	No need for MHS[a]		Met need for MHS[a]			No need for MHS[a]		Met need for MHS[a]			
	OR	95%CI	OR	95%CI		OR	95%CI	OR	95%CI		
Gender (male)	0.66	0.42 - 1.05	0.83	0.49 – 1.35							
Age	**1.03**	**1.01 – 1.05**	1.02	0.99 – 1.04		**1.03**	**1.02 – 1.05**	1.02	1.00 – 1.04		
Country of birth (Dutch)	1.17	0.60 – 2.30	1.00	0.50 – 2.07							
Education	0.99	0.92 – 1.05	0.97	0.90 – 1.04							
Housing (independent)	0.90	0.31 – 2.62	0.82	0.27 – 2.61							
Income level [b] Usually some money left	0.96	0.43 – 2.14	1.31	0.51 – 3.35							
Just enough	0.98	0.43 – 2.20	1.34	0.52 – 3.43							
Eye disorder (Macular Degeneration)	0.86	0.52 – 1.43	0.95	0.54 – 1.66							
Time of onset of visual loss [c] 0-3 years	1.00	0.99 – 1.01	1.00	0.99 – 1.01							
4-7 years	0.98	0.96 – 1.02	0.97	0.95 – 1.02							
8-18 years	1.01	0.99 – 1.01	0.99	0.98 – 1.00							
Visual acuity [d] Normal visual acuity	0.94	0.48 – 1.82	0.60	0.27 – 1.31							
Mild vision loss	1.21	0.68 – 2.17	0.99	0.52 – 1.88							
Severity depression/anxiety [e] No symptoms	**8.07**	**4.02 – 16.21**	**6.87**	**3.05 –15.48**		**6.07**	**3.33 – 11.06**	**5.72**	**2.76 –11.84**		
Subthreshold	**2.04**	**1.03 – 4.04**	**2.33**	**1.06 – 5.13**		**1.92**	**1.05 – 3.50**	**2.60**	**1.27 – 5.31**		
Comorbid depression and anxiety	6.16	**1.27 – 29.80**	2.42	0.60 – 9.74		**4.26**	**1.15 – 15.80**	1.69	0.49 – 5.78		
History of major depressive disorder	0.95	0.50 – 1.81	0.52	0.27 – 1.00		1.01	0.58 – 1.77	**0.51**	**0.28 – 0.90**		
Other comorbid disorders	1.13	0.92 – 1.39	1.02	0.81 – 1.28							
Perceived health status	**4.12**	**1.55 – 11.06**	1.16	0.42 – 3.25		**3.94**	**1.74 – 8.94**	1.49	0.62 – 3.59		

Bold is significant at *P*≤0.05. MHS mental health services.
Reference group: [a]in need of mental health services; [b]not enough money; [c]19-79 years; [d]low vision/blindness; [e]disorder

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Discussion

The present study confirms that depression and anxiety are major problems in visually impaired older adults; about 35% suffered from subthreshold depression and/or anxiety, and 13% had an actual depressive and/or anxiety disorder. This is substantially higher than the prevalence in general older adult populations.[5,7,10-12] However, visually impaired older adults often do not receive any form of mental health services, even though they had all been in contact with professionals from low vision rehabilitation organisations and in most cases with their general practitioner and ophthalmologist. This is underlined by other studies in older populations[26,27,31,32] and is a matter of great concern, because of the detrimental impact of depression and anxiety in this inherently vulnerable population.[19-21]

More than half of the participants with a depressive and/or anxiety disorder reported to be in need of mental health services; a finding consistent with other studies.[26,31,32,47] Participants with more severe depression and/or anxiety, comorbid depression and anxiety, and a lower perceived health status more frequently expressed a need for professional mental health services. These *clinical need factors* were also found in other studies.[26,28,31,32,47] Furthermore, people with a history of major depressive disorder were less often in need of mental health services as their needs were more often fully met, indicating that these people already know where to find the required services. In addition, the *predisposing factor* age was significantly related to perceived need for mental health services. Older participants were more likely to express no need for mental health services than younger participants; a finding also reported by others.[26,32,47-50] Possible explanations for this might be that older adults will manage with gained life experience or more often indicate the preference to solve problems themselves. They grew up in a time-period in which mental health problems were often not recognised as medical conditions and it was not common to openly talk about it. This may cause present difficulty of acknowledging a need for mental health services. Differences between participants in 'working ages' and 'non-working ages', which were both included in the present study, might also have led to differences in mental health needs as studies show that these groups have different life goals and rehabilitative needs.[51,52]

The main reason for an unfulfilled need for mental health services was lack of knowledge, indicating that visually impaired older adults do not have sufficient knowledge about mental illnesses and treatment possibilities. In studies in the general older population this reason was mentioned less often.[26,31] This lack of knowledge might be due to the focus of both patients and professionals on physical symptoms rather than psychological issues and the difficulty of distinguishing depression and anxiety from normal grief associated with vision loss.[23-25] Therefore, feasible screening and monitoring procedures should become a routine part of low vision rehabilitation care. Professionals may be stimulated to use brief, validated screening tools to be able to detect symptoms of depression and anxiety. A short version of the patient health questionnaire (PHQ), which can also be used by non-mental health staff, might be suited for this purpose.[53,54]

The second most frequently mentioned reason for not receiving (sufficient) mental health services was self-reliance, indicating that a proportion of the study population rather solves problems themselves. In at least two studies in the general population this reason was mentioned most often.[31,49] Professionals can stimulate these patients by promoting patient empowerment, in which patients are offered guidance in solving their problems corresponding to their own need of self-reliance, whilst under the professional supervision of healthcare providers. Patient empowerment is already being applied in many different fields of healthcare.[55] Guided self-help, a structured treatment method based on cognitive behavioural therapy (CBT) with limited professional guidance, is one of the possibilities.[33,56,57]

It might also be possible that these responses (i.e. lack of knowledge and self-reliance) are caused by patients' difficulty of acknowledging a need for mental health services. Professionals should be aware of this possibility and stimulate patients in overcoming this difficulty.

Strengths and limitations

The present study is the first to investigate the utilisation of, the perceived need for and barriers to receive mental health services in a visually impaired older population, based on the widely used framework of Andersen's Behavioural Model. The outcomes might not only be used for research, but also for clinical practice as it offers important indications to direct visually impaired older adults to the services they need to improve their psychological wellbeing. Validated questionnaires were used to analyse perceived need for mental health services and potential related factors, which allows for comparison with other studies. In addition, a large number of patients were included, which increases the reliability and generalisability of the results.

However, the results should be interpreted with caution. First, the present study was based on a cross-sectional design giving no indication of the sequence of events. Therefore, it is impossible to infer causality between the investigated factors and the outcome measure. Second, patients from the present study may differ from individuals in the general visually impaired population. Study participants may for instance be relatively healthier as they were able to take part in the interviews and were not cognitively impaired. In addition, they might have had higher needs for- and better access to healthcare as they were all patients of low vision rehabilitation services. Third, non-responders were significantly older than responders, and older patients proved to be less often in need of mental health services. This may have resulted in an overestimation of the number of participants found to be in need of mental health services. Further studies are needed to investigate longitudinal data to determine predictors of perceived need for mental health services in this population, in which non-clinical participants might be included and additional related factors (such as other psychiatric disorders) might be investigated.

Conclusion

Visually impaired older adults who suffer from depression and/or anxiety often do not receive mental health services. However, many of them do perceive a need for it. Participants who were most inclined to be in need of mental health services had more severe symptoms of depression and/or anxiety, comorbid depression and anxiety, no history of major depressive disorder, a lower perceived health status, and a younger age. Older participants were more likely to express no need for mental health services, independent of depression/anxiety severity, which may be caused by patients' difficulty of acknowledging a need for mental health services. Professionals should be aware of this possibility and stimulate patients in overcoming this difficulty. The main reasons for an unfulfilled need for mental health services were lack of knowledge and self-reliance. Findings support the implementation of screening and monitoring procedures and patient empowerment within low vision rehabilitation, for which extensive research is warranted.

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