

The University of Hong Kong Public Opinion Programme

Survey on Socio-Economic Impact of Age-related Macular Degeneration to Patients' Families



Survey Report

Jointly compiled by

CHUNG Ting-Yiu Robert, PANG Ka-Lai Karie
and TONG Yuk-Wa Joseph

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Everything in this publication is the work of individual researchers, and does not represent the stand of the University of Hong Kong. Dr Robert Chung is fully responsible for the work of the POP.

I **Research Background**

- 1.1 In July 2007, *Retina Hong Kong* commissioned POP to conduct an opinion survey entitled “Survey on Socio-economic Impact of Age-related Macular Degeneration to Patients’ Families”. The targets are aged-related macular degeneration (AMD) patients or their family members. The objectives of this survey are to look into the overall impacts of AMD on the patients’ families, the financial burden brought by AMD and expectations from patients’ families.

- 1.2 The research instrument used in this study was designed by the POP Team after consulting *Retina Hong Kong*, whilst fieldwork operations and data analysis were also conducted independently by the POP Team, without interference from any outside party. In other words, POP was given full autonomy to design and conduct the survey, and POP would take full responsibility for all the findings reported herewith.

II Research Design

- 2.1 The contact list comprising a total of 121 AMD patients was supplied by *Retina Hong Kong*. Telephone interviews were conducted by interviewers under close supervision. All data were collected by our interviewers using a Computer Assisted Telephone Interview (CATI) system which allowed real-time data capture and consolidation. To ensure data quality, on top of on-site supervision, voice recording, screen capturing and camera surveillance were used to monitor the interviewers' performance.
- 2.2 The fieldwork was conducted during the period of August 17 to October 5, 2007. A total of 101 AMD patients or their family members were successfully interviewed and their respective sub-sample sizes were 84 (83.2%) and 17 (16.8%). As shown from the calculation in Appendix I, the overall effective response rate of this survey reached as high as 94.4% (Table 2), and the standard sampling error for percentages based on this sample was less than 5.0 percentage points. In other words, if the target respondents had been drawn randomly, the sampling error for all percentages would have been less than plus/minus 10.0 percentage points at 95% confidence level.
- 2.3 Of the 121 contact numbers approached by the research team, 3 (2.5%) were confirmed to be ineligible as there was no AMD patient available in such household, while 7 (5.8%) were invalidated before the research team could confirm their eligibility and 10 (8.3%) cases failed to complete the interview though respondents' eligibility was confirmed. The remaining 101 were successful cases (83.5%; Table 1).

III Research Findings

This survey questionnaire comprises three main parts, namely “Overall impacts of AMD on patients’ families”, “Financial burden/impacts on patients’ families brought by AMD” and “Expectation from AMD patients’ families”. Key findings are summarized below. Cross-references could be made with the tables in Appendix 2.

(I) Overall impacts of AMD on patients’ families

- 3.1 Of the 101 patients’ families interviewed, findings showed that 50% of the AMD patients have suffered from this disease for 4 years or less, one-fifth (20%) have had such disease for 5-9 years while one-fourth (25%) have suffered from AMD for 10 years or more. Specifically, those who have had AMD for “less than a year” and “2 years” accounted for the largest proportions with 19% and 10% respectively. Excluding those who could not give definite answers, patients have suffered from AMD, on average, for 5.8 years (standard error: 0.6 years; Table 3).
- 3.2 The survey continued to ask respondents the overall impacts of AMD brought to their families. As for influences of AMD on patients’ daily activities, results showed that 61% of them “could not watch TV clearly”, 53% “could not read newspapers or books without a magnifier”. 35% also pointed out that they “could not read road signs/bus route number” while another 13% said they “could not go out alone”. Besides, a few number of respondents said they “could not figure out the height of staircases” (4%) and some of them “could not see people’s face clearly” (3%). Nevertheless, 24% patients said AMD had no particular impacts on their daily lives (Table 4).
- 3.3 Meanwhile, the survey also found out that after the confirmed diagnosis of AMD, the patients were most worried about the “continuous deterioration of their eyesight and eventually becoming blind” (77%), followed by “the loss of physical mobility / ability to make a living” (62%) while “the financial burden caused by the medical expenses” (58%) came third. At the same time, 43% did not want “to become a family burden who needed to be taken care of in daily life” while 21% feared of “being discriminated or repulsed” by other people in society. However, 14% got no worry at all. (Table 5).

3.4 The survey then requested all respondents to use a scale of 0-10 to rate the overall impacts of AMD brought to their whole families, including their daily lives, social activities and so on, with 0 indicating the impacts being absolutely minimal, 10 indicating the impacts being absolutely significant and 5 indicating half-half. Findings showed that over 60% (62%) of the respondents gave “0-5” marks while the most popular scores were “5” and “0” marks, which took up 33% and 16% respectively. Those who scored “6-10” marks accounted for 38% with “8” marks (12%) being the most frequently cited score. Taking an average of 98 valid raters, the mean score was 5.07 marks (standard error: 0.31 marks). In other words, the overall impacts of AMD on patients’ families were just mediocre (Table 6).

(II) Financial burden/impacts on patients’ families brought by AMD

3.5 The second part mainly focused on the financial burden imposed by AMD onto the patients’ families. Nearly 90% (88%) of the patients required medical consultation and treatment due to this disease while 12% did not. Among the 12 patients who received no treatment before, 5 (46%) of them believed “AMD was not curable”, 4 (36%) said they had “no such need”, 2 (18%) said they “could not afford the medical expenses” while 1 refused to provide the reasons behind (Table 7 and 8).

3.6 The survey went on to ask if the patients had bought any instruments for assistance use after the confirmed diagnosis of AMD. Findings showed that 62% did not buy any aiding-instruments. Among those who had, “magnifiers” topped the list which captured one-third of the sample. Besides, 6% had purchased “closed-circuit TV (CCTV)” and the same proportion got “white canes”. Those who had bought “filter glasses” or “telescopes” accounted for 5% and 4% respectively (Table 9).

3.7 Of the total sample, 20% of the AMD patients had to visit doctors after getting injured caused by their weakened eyesight. Besides, 5% of the families interviewed had hired a private nurse or domestic helper in order to take care of the AMD patients but the remaining 95% did not hire any assistant (Table 10 and 11).

3.8 As shown from the above findings that most of the patients, after suffering from AMD, would need to receive medical treatment while some of them had also

purchased assisting instruments, a few patients' families even hired a private nurse or domestic helper, then how much in total the patients' families had to spend on AMD treatment each year? Results showed that 23% of them spent "\$5,000 or below" each year while those who said "\$5,001 to \$10,000" and "\$10,001 to \$20,000" both accounted for 14% of the total sample. Another 11% reported that the annual medical expenses amounted to as high as "\$30,001 to \$40,000". On the other hand, 13% said they spent none on treating AMD. Taking an overall average of the 101 families interviewed, each had to spend \$19,500 on treating AMD per year (standard error: \$2,900; Table 12).

- 3.9 As for the 88 patients who had incurred medical expense to treat AMD, 35% said their household expenditure had increased by "10% or below" due to AMD, 11% claimed their family expenses were up by "11% to 20%". A respective of 9% and 7% said their expenses surged by "21% to 30%" and "31% to 40%" while just a small proportion said the increment was "41% to 50%" or even "over 50%" (both at 2%). Overall speaking, excluding those who failed to provide a definite answer, the annual household expenditure of these patients' families had increased by 19.0% on average (standard error: 2.5%, Table 13).
- 3.10 To cope with the extra expenses, 44% of the respondents said they had "cut their daily expenditure, like dining out and shopping less", 11% needed to "apply for government subsidies", 7% had to "seek financial support from relatives or friends/bank/financial company" while a same proportion of respondents had "taken up (more) part time jobs to earn more income". Meanwhile, over half of the respondents (52%) did not have any of the above-mentioned experiences (Table 14).
- 3.11 Similarly, all respondents were asked to use a scale of 0-10 to rate how heavy the burden AMD had placed on their families' financial well-being, with 0 indicating no burden at all, 10 indicating extremely heavy and 5 indicating half-half. Results showed that 51% opted for "0-4" marks, in which 19% gave "0" mark. The proportion of respondents who thought the burden was heavy (i.e. giving "6-10" marks) captured 18% while "5" marks, the most commonly cited figure, accounted for another 32%. Taking an average of all 97 valid raters, the mean score was 3.88 marks (standard error: 0.29 marks). Hence, judging from this figure, the financial burden caused by AMD to the patients' families seemed not that heavy.

3.12 Assumingly there was such a need in future, did the respondents know through what channels or what organizations they could apply for financial assistance? Findings of this survey showed that only 19% had a clue while the remaining 81% had no idea at all. For those 18 knowledgeable respondents, all of them knew they could apply through “Social Welfare Department” for financial assistance (Table 16).

(III) Expectation from AMD patients’ families

3.13 The last part of this survey attempted to probe for what kind of assistance or support the AMD patients and their families would call for in order to lessen their burdens. Results revealed that the majority would like the government to “provide more direct subsidies to the patients’ families” (27%), followed by “offering the latest information related to AMD treatment/catering/health care” (17%) while “increasing subsidies to organizations specializing in AMD” (9%) and “offering supplementary instruments for patients to cope with the changes in daily lives” (9%) formed the next tier. Besides, a respective of 7% and 6% hoped for “new treatment/medicine for AMD” and “more publicity in society in order to raise the social awareness towards AMD”. For other open answers provided by the respondents, please refer to Table 17 in appendix 2. Interestingly, 38% said they needed no assistance for the time being (Table 17).

IV **Concluding Remarks**

- 4.1 Since the contact list of this survey was supplied by *Retina Hong Kong* and it was not drawn from the general public randomly, the findings may therefore be biased. However, because patients' medical records are classified as sensitive information, it will be difficult to adopt random sampling. Therefore, with contacts provided by professional associations, the results should be regarded as valuable references to a certain extent.
- 4.2 This AMD survey showed that though the overall impacts of AMD on patients' families were just mediocre, patient's daily lives were greatly affected, which mainly concerned watching TV clearly and reading. Meanwhile, only one-fourth of them claimed AMD caused no impacts at all to their daily lives. It is also worth mentioning that many AMD patients were worried about the continuous deterioration of their eyesight, which might eventually go blind.
- 4.3 As regards the economic burden, though most of the respondents expressed it was not that heavy, findings of this survey showed that patients, taking an average, spent about \$20,000 per year on treating AMD, or an increment of approximately 20% to their overall household expense, which is not a small number. Besides, over 80% of the respondents had no idea at all through what channel they could apply for financial assistance when needed. This situation calls for attention.
- 4.4 After all, this survey is more of exploratory in nature, but the data collected should serve as good references to *Retina Hong Kong* when paving way for its work direction in future.

Appendix I

Contact Information

Table 1 *Contact information*

	Frequency	Percentage
Respondents' ineligibility confirmed	3	2.5%
<i>Fax/ data line</i>	0	0.0%
<i>Invalid number</i>	0	0.0%
<i>Call-forwarding/ mobile/ pager number</i>	0	0.0%
<i>Non-residential number</i>	0	0.0%
<i>Special technological difficulties</i>	1	0.8%
<i>No eligible respondents</i>	2	1.7%
Respondents' eligibility not confirmed	7	5.8%
<i>Line busy</i>	2	1.7%
<i>No answer</i>	3	2.5%
<i>Answering device</i>	1	0.8%
<i>Call-blocking</i>	0	0.0%
<i>Language problem</i>	1	0.8%
<i>Interview terminated before the screening question</i>	0	0.0%
<i>Others</i>	0	0.0%
Respondents' eligibility confirmed, but failed to complete the interview	10	8.3%
<i>Household-level refusal</i>	1	0.8%
<i>Known respondent refusal</i>	0	0.0%
<i>Appointment date beyond the end of the fieldwork</i>	1	0.8%
<i>Partial interview</i>	5	4.1%
<i>Miscellaneous</i>	3	2.5%
Successful cases	101	83.5%
Total	121	100.0%

Table 2 *Calculation of effective response rate*

Effective response rate	
=	$\frac{\text{Successful cases}}{\text{Successful cases} + \text{Partial interview} + \text{Refusal cases by eligible respondents} + \text{Refusal cases by prorated-eligible respondents}}$
=	$\frac{101}{101 + 5 + 1 + 0[(101 + 5 + 1) / (101 + 5 + 1 + 2)]^*}$
=	94.4%
	<i>*Figure obtained by prorata</i>

Appendix II

Frequency Tables

Table 3 [Q1] First of all, how long have (has) you (your family member) been suffering from AMD?

	Frequency	Percentage (Base=101)
Less than a year	19	18.8%
1 year	7	6.9%
2 years	10	9.9%
3 years	6	5.9%
4 years	9	8.9%
5 years	7	6.9%
6 years	4	4.0%
7 years	5	5.0%
8 years	3	3.0%
9 years	1	1.0%
10 years	7	6.9%
11 years	3	3.0%
12 years	5	5.0%
13 – 20 years	6	5.9%
Over 20 years	4	4.0%
Don't know/hard to say/forgot	5	5.0%
Total	101	100.0%
Mean	5.8 years	
Standard error	0.6 years	
Base	96	

Table 4 [Q2] Has AMD affected your (your family member's) daily activities related to vision? (Interviewers read out answers and multiple responses allowed.)

	Frequency	% of responses (Base=195)	% of cases (Base=99)
At home: Cannot watch TV clearly	60	30.8%	60.6%
At home: Cannot read newspapers or books without a magnifier	52	26.7%	52.5%
Outside home: Cannot read road signs/ bus route number	35	17.9%	35.4%
Outside home: Cannot go out alone	13	6.7%	13.1%
Cannot figure out the height of staircases	4	2.1%	4.0%
Cannot see people's face clearly	3	1.5%	3.0%
Others (See Table 4a)	4	2.1%	4.0%
No impacts	24	12.3%	24.2%
Total	195	100.0%	
<i>Missing</i>	2		

Table 4a [Q2] Has AMD affected your (your family member's) daily activities related to vision? (Others)

	Frequency
Cannot see straight lines	2
Cannot differentiate similar colours	1
Shed tears no matter what the patient does	1
Total	4

Table 5 [Q3] After the confirmed diagnosis of AMD, what do (does) you (your family member) worry most? (Read out answers, order to be randomized by computer, multiple responses allowed)

	Frequency	% of responses (Base=280)	% of cases (Base=101)
The continuous deterioration of their eyesight and eventually becoming blind	78	27.9%	77.2%
The loss of physical mobility / ability to make a living	63	22.5%	62.4%
The financial burden caused by the medical expenses	59	21.1%	58.4%
To become a family burden who needs to be taken care of in daily life	43	15.4%	42.6%
To be discriminated/repulsed by other people in society	21	7.5%	20.8%
Others (See Table 5a)	2	0.7%	2.0%
No worry	14	5.0%	13.9%
Total	280	100.0%	

Table 5a [Q3] After the confirmed diagnosis of AMD, what do (does) you (your family member) worry most? (Others)

	Frequency
Cannot afford daily expenses	1
Worry the eye with no problem will suffer as well	1
Total	2

Table 6 [Q4] Please use a scale of 0-10 to rate the overall impacts of AMD brought to your whole family, including your daily lives, social activities and so on, with 0 indicating the impacts being absolutely minimal, 10 indicating the impacts being absolutely significant and 5 indicating half-half.

	Frequency	Percentage (Base=98)
0	16	16.3%
1	1	1.0%
2	4	4.1%
3	4	4.1%
4	4	4.1%
5	32	32.7%
6	4	4.1%
7	9	9.2%
8	12	12.2%
9	3	3.1%
10	9	9.2%
Total	98	100.0%
<i>Missing</i>	3	
Mean	5.07	
Standard error	0.31	
Base	98	

Table 7 [Q5] Have (has) you (your family member) received medical consultation and treatment due to this disease?

	Frequency	Percentage (Base=101)
Yes (skip to Q7)	89	88.1%
No	12	11.9%
<i>Total</i>	101	100.0%

Table 8 [Q6] (Only ask those who answer “no” at Q5) Why don't (doesn't) you (your family member) receive any kind of treatment?

	Frequency	% of response (Base=11)	% of cases (Base=11)
Perceive AMD is not curable	5	45.5%	45.5%
Perceive there is no such need	4	36.4%	36.4%
Cannot afford the medical expenses	2	18.2%	18.2%
<i>Total</i>	11	100.0%	
<i>Missing</i>	1		

Table 9 [Q7] Have (Has) you (your family member) bought any instruments for assistance use after the confirmed diagnosis of AMD?

	Frequency	% of responses (Base=118)	% of cases (Base=99)
Magnifiers	33	28.0%	33.3%
Closed-circuit TV (CCTV)	6	5.1%	6.1%
White canes	6	5.1%	6.1%
Filter glasses	5	4.2%	5.1%
Telescopes	4	3.4%	4.0%
Others (See Table 9a)	3	2.5%	3.0%
Bought no instruments	61	51.7%	61.6%
<i>Total</i>	118	100.0%	
<i>Missing</i>	2		

Table 9a [Q7] Have (Has) you (your family member) bought any instruments for assistance use after the confirmed diagnosis of AMD? (Others)

	Frequency
Talking clock	1
Electronic clock	1
Talking software for PC	1
Total	3

Table 10 [Q8] Have (Has) you (your family member) visited doctors after getting injured caused by your (his/her) weakened eyesight?

	Frequency	Percentage (Base=101)
Yes	20	19.8%
No	81	80.2%
Total	101	100.0%

Table 11 [Q9] Do your family hire a private nurse or domestic helper because you (your family member) suffer(s) from this disease?

	Frequency	Percentage (Base=101)
Yes	5	5.0%
No	96	95.0%
Total	101	100.0%

Table 12 [Q10] On average, how much do your family have to spend on AMD treatment each year? Please include extra expenses like medicine, consulting doctors, purchasing aiding-instruments, hiring a private nurse/domestic helper and so on. (If patients receive no treatment or receive subsidies from the government, enter "0" and skip to Q12)

	Frequency	Percentage (Base=101)
No medical expenses	13	12.9%
\$5,000 or below	23	22.8%
\$5,001 - \$10,000	14	13.9%
\$10,001 - \$20,000	14	13.9%
\$20,001 - \$30,000	4	4.0%
\$30,001 - \$40,000	11	10.9%
\$40,001 - \$50,000	4	4.0%
Over \$50,001	7	6.9%
Don't know/hard to say	11	10.9%
Total	101	100.0%
Mean	\$19,519	
Standard error	\$2,914	
Base	90	

Table 13 [Q11] How far do these medical expenses increase your overall household expenditure?

	Frequency	Percentage (Base=88)
10% or below	31	35.2%
11% - 20%	10	11.4%
21% - 30%	8	9.1%
31% - 40%	6	6.8%
41% - 50%	2	2.3%
Over 50%	2	2.3%
Don't know/hard to say	29	33.0%
Total	88	100.0%
Mean	19.0%	
Standard error	2.5%	
Base	59	

Table 14 [Q12] In order to treat AMD, have your family (Read out answers, order to be randomized by computer, multiple responses allowed)

	Frequency	% of response (Base=121)	% of cases (Base=101)
Cut your daily expenditure (like: dining out, shopping less)	44	36.4%	43.6%
Applied for (any sort of) government subsidies	11	9.1%	10.9%
Sought financial support from relatives or friends/bank/finance company	7	5.8%	6.9%
Taken up (more) part time jobs	7	5.8%	6.9%
None of the above	52	43.0%	51.5%
Total	121	100.0%	

Table 15 [Q13] Please use a scale of 0-10 to rate how heavy the burden AMD has placed on your financial well-being, with 0 indicating no burden at all, 10 indicating extremely heavy and 5 indicating half-half.

	Frequency	Percentage (Base=97)
0	18	18.6%
1	3	3.1%
2	13	13.4%
3	10	10.3%
4	5	5.2%
5	31	32.0%
6	1	1.0%
7	5	5.2%
8	4	4.1%
9	1	1.0%
10	6	6.2%
Total	97	100.0%
Missing	4	
Mean	3.88	
Standard error	0.29	
Base	97	

Table 16 [Q14] If needed, do you know through what channel or what organizations you can apply for financial assistance?

	Frequency	Percentage (Base=97)
Yes*	18	18.6%
No	79	81.4%
Total	97	100.0%
Missing	4	

Table 17 [Q15] Finally, could you please tell me what kind of assistance you would like to call for, which can be in any forms like materially, financially, mentally. Anything counts as long as you consider it necessary in daily life. (No need to read out answers, multiple responses allowed. Probed by “anything else” until respondents say “no more”.)

	Frequency	% of responses (Base=129)	% of cases (Base=101)
Increase Government’s direct subsidies to patients’ families	27	20.9%	26.7%
Offer the latest information related to AMD treatment/catering/health care (eg, forum and exhibition)	17	13.2%	16.8%
Increase subsidies to organizations specializing in AMD	9	7.0%	8.9%
Offer supplementary instruments for patients to cope with changes in daily lives	9	7.0%	8.9%
Have new treatment/medicine	7	5.4%	6.9%
Increase the publicity in society in order to raise the social awareness towards AMD	6	4.7%	5.9%
Improve community/transport facilities for the convenience of patients going out	4	3.1%	4.0%
Offer family counselling services	4	3.1%	4.0%
Provide domestic helpers to help look after the patients	2	1.6%	2.0%
Others (See Table 17a)	3	2.3%	3.0%
Need no assistance	38	29.5%	37.6%
Don’t know/hard to say	3	2.3%	3.0%
Total	129	100.0%	

* For those 18 respondents who had a clue, all said they could apply for financial assistance through “Social Welfare Department”.

Table 17a [Q15] Finally, could you please tell me what kind of assistance you would like to call for, which can be in any forms like materially, financially, mentally. Anything counts as long as you consider it necessary in daily life. (No need to read out answers, multiple responses allowed. Probed by “anything else” until respondents say “no more”). (Others)

	Frequency
Can see doctor regularly	1
To provide more entertainments for patients	1
To know more patients with the same disease, so that patients can interact with each other to seek more treatment.	1
Total	3

Appendix III

Respondents' Demographic Profile

Table 18 (Patient) Gender

	Frequency	Percentage (Base=101)
Male	47	46.5%
Female	54	53.5%
Total	101	100.0%

Table 19 Are (Is) you (your family member) suffering from wet AMD or dry AMD?

	Frequency	Percentage (Base=100)
Wet AMD	25	25.0%
Dry AMD	21	21.0%
Don't know	54	54.0%
Total	100	100.0%
<i>Missing</i>	<i>1</i>	

Table 20 (Patient) Age

	Frequency	Percentage (Base=101)
50 or below	2	2.0%
51-55	14	13.9%
56-60	14	13.9%
61-65	8	7.9%
66-70	13	12.9%
70 above	50	49.5%
Total	101	100.0%

Table 21 Is patient working?

	Frequency	Percentage (Base=101)
Full time	12	11.9%
Part time	3	3.0%
Unemployed	5	5.0%
Full time Housewives	24	23.8%
Retired	57	56.4%
Total	101	100.0%

Table 22 Household monthly income

	Frequency	Percentage (Base=87)
No income	14	16.1%
\$5,000 or below	10	11.5%
\$5,001 - \$10,000	19	21.8%
\$10,001 - \$20,000	18	20.7%
\$20,001 - \$30,000	11	12.65
\$30,001 - \$50,000	11	12.6%
\$50,000 above	4	4.6%
Total	87	100.0%
<i>Missing</i>	<i>14</i>	

Appendix IV

Questionnaire

The University of Hong Kong Public Opinion Programme

Retina Hong Kong

Jointly organized

Survey on Socio-economic Impact of
Age-related Macular Degeneration to
Patients' Families

English Questionnaire (Final draft)

August 13, 2007

Part I Introduction

Good evening! My name is [interviewer's name]. I am an interviewer at the Public Opinion Programme of the University of Hong Kong. We are conducting a survey on age-related macular degeneration (AMD). This survey only takes up a couple of minutes. The information you provide will be kept strictly confidential and data collected will only be used for analysis. Is it okay for you to participate in this survey?

- Yes
- No Interview ends. Thank you and bye. (skip to end)

Part II Selection of Respondents

[S1] As the target of this interview are AMD patients, are you diagnosed by an eye doctor as an AMD patient?

- Yes, and is available for an interview → Q1
- Yes, but is not available/not willing to be interviewed → S2
- No → S2
- Refuse to answer Interview ends. Thank you and bye. (skip to end)

[S2] Then is there anyone in this household who looks after you/the patient now available for an interview?

- Yes
- No Interview ends. Thank you and bye. (skip to end)
- Refuse to answer Interview ends. Thank you and bye. (skip to end)

Part III Opinion Questions

I) Overall impacts of AMD on patients' families

[Q1] First of all, how long have (has) you (your family member) been suffering from AMD?

Less than a year

_____ year(s) (Input exact figure, 1-20)

Over 20 years

Don't know/hard to say/forgot

Refuse to answer

[Q2] Has AMD affected your (your family member's) daily activities related to vision? (Interviewers read out answers and multiple responses allowed.)

At home:

Cannot read newspapers or books without a magnifier

Cannot watch TV clearly

Outside home:

Cannot go out alone

Cannot read road signs

Others (Please specify : _____)

No impacts

Don't know/hard to say

Refuse to answer

[Q3] After the confirmed diagnosis of AMD, what do (does) you (your family member) worry most? (Read out answers, order to be randomized by computer, multiple responses allowed)

The continuous deterioration of their eyesight and eventually becoming blind

To become a family burden who needs to be taken care of in daily life

The financial burden caused by the medical expenses

The loss of physical mobility / ability to make a living

To be discriminated/repulsed by other people in society

Others (Please specify : _____)

No worry

Don't know/hard to say

Refuse to answer

[Q4] Please use a scale of 0-10 to rate the overall impacts of AMD brought to your whole family, including your daily lives, social activities and so on, with 0 indicating the impacts being absolutely minimal, 10 indicating the impacts being absolutely significant and 5 indicating half-half.

_____(Input exact figure)

Don't know/hard to say

Refuse to answer

II) Financial burden/impacts on patients' families brought by AMD

[Q5] Have (has) you (your family member) received medical consultation and treatment due to this disease?

Yes (skip to Q7)

No

Refuse to answer (skip to Q7)

[Q6] (Only ask those who answer “no” at Q5) Why don't (doesn't) you (your family member) receive any kind of treatment?

Cannot afford the medical expenses

Perceive AMD is not curable

Perceive it is too troublesome

Perceive there is no such need

Others (Please specify : _____)

Don't know/hard to say

Refuse to answer

[Q7] Have (Has) you (your family member) bought any instruments for assistance use after the confirmed diagnosis of AMD?

Closed-circuit TV (CCTV)

Magnifiers

Telescopes

White canes

Filter glasses

Others (Please specify : _____)

Bought no instruments

Don't know/hard to say

Refuse to answer

[Q8] Have (Has) you (your family member) visited doctors after getting injured caused by your (his/her) weakened eyesight?

Yes

No

Refuse to answer

[Q9] Do your family hire a private nurse or domestic helper because you (your family member) suffer(s) from this disease?

Yes

No

Refuse to answer

[Q10] On average, how much do your family have to spend on AMD treatment each year? Please include extra expenses like medicine, consulting doctors, purchasing aiding-instruments, hiring a private nurse/domestic helper and so on. (If patients receive no treatment or receive subsidies from the government, enter "0" and skip to Q12)

_____(Input exact figure)

Don't know/hard to say

Refuse to answer

[Q11] How far do these medical expenses increase your overall household expenditure?

_____ (Input percentage)

Don't know/hard to say

Refuse to answer

[Q12] In order to treat AMD, have your family (Read out answers, order to be randomized by computer, multiple responses allowed)

Applied for (any sort of) government subsidies

Sought financial support from relatives or friends/bank/finance company

Taken up (more) part time jobs

Cut your daily expenditure (like: dining out, shopping less)

None of the above

Others (Please specify : _____)

Don't know/hard to say

Refuse to answer

[Q13] Please use a scale of 0-10 to rate how heavy the burden AMD has placed on your financial well-being, with 0 indicating no burden at all, 10 indicating extremely heavy and 5 indicating half-half.

_____(Input exact figure)

Don't know/hard to say

Refuse to answer

[Q14] If needed, do you know through what channel or what organizations you can apply for financial assistance?

Yes (Please specify : _____)

No

Refuse to answer

III) Expectations from AMD patients' families

[Q15] Finally, could you please tell me what kind of assistance you would like to call for, which can be in any forms like materially, financially, mentally. Anything counts as long as you consider it necessary in daily life. (No need to read out answers, multiple responses allowed. Probed by “anything else” until respondents say ”no more”.)

Increase Government's direct subsidies to patients' families

Increase subsidies to organizations specializing in AMD

Provide domestic helpers to help look after the patients

Offer supplementary instruments for patients to cope with changes in daily lives

Improve community/transport facilities for the convenience of patients going out

Offer family counselling services

Offer the latest information related to AMD treatment/catering/health care (eg, forum and exhibition)

Increase the publicity in society in order to raise the social awareness towards AMD

Need no assistance

Others (Please specify : _____)

Don't know/hard to say

Refuse to answer

Part IV Demographics

Lastly, I would like to ask you for some personal information for further analysis.

[DM1] (Patient) Gender

Male

Female

[DM 2] Are (Is) you (your family member) suffering from wet AMD or dry AMD?

Wet AMD

Dry AMD

Don't know

Refuse to answer

[DM3] (Patient) Age

50 or below

51-55

56-60

61-65

66-70

Over 70

Refuse to answer

[DM4] Is patient working?

Full time

Part time

Unemployed

Housewife

Retired

Refuse to answer

[DM5] Household monthly income

- No income
- \$5,000 or below
- \$5,001 - \$10,000
- \$10,001 - \$20,000
- \$20,001 - \$30,000
- \$30,001 - \$50,000
- Over \$50,000
- Refuse to answer

Thank you for your time. If you have any questions regarding this interview, you can contact our supervisor at XXXX XXXX or call XXXX XXXX during office hours to verify this interview's authenticity and confirm my identity. Bye bye.

***** **End of interview** *****