

Primary care barriers to cataract surgery in the eastern zone of Peninsular Malaysia: an interpretative phenomenological analysis

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ABSTRACT

Objective: Cataract is the leading cause of blindness in Malaysia. There is an alarming backlog of cataract extraction surgery as the majority believes they did not require surgery. This study aimed to explore the barriers at the primary care level to cataract surgery from the perspective of patients with severe cataract blindness.

Methods: Eleven participants were involved in this qualitative research which utilised the interpretative phenomenological analysis approach more renowned in health psychology research. All interviews conducted at their home. The interviews were recorded, typed verbatim, and the transcripts were analysed using NVivo software version 8.0.

Results: The main barriers identified at the primary care level were 1) nondisclosure of their visual problems originated from their belated needs for better sight, delayed awareness of their visual status and social stigma and 2) patient-provider-related issues namely miscommunication and delayed referral. The first main theme explains their belief for not requiring surgery. This has led to their delayed awareness and impeded disclosure of their visual problems to family members or primary care providers. The second main theme reflects the provider-patient-related issues which retarded cataract detection and referral process required for earlier cataract extraction surgery.

Conclusion: Thus, the appropriate approach targeting these specific barriers at primary care level will be able to detect, motivate and assist patients for early uptake of cataract extraction surgery to improve their vision and prevent severe blindness.

KEY WORDS:

Cataract; blindness; cataract extraction; barriers; primary health care; qualitative research

INTRODUCTION

The second National Eye Survey (NES2) in 2014 that was conducted simultaneously in six zones, revealed cataract as the leading cause of blindness for Malaysia.¹ The adjusted

national prevalence of blindness was 0.8%, with 1.0 % in the Eastern zone, the third highest following the Northern and Sabah zones.¹ The total number of cataract extraction surgery backlog for the whole country was more than six hundred thousand with the majority of them believed they did not require surgery.¹ Their delay in seeking treatment seemed to result from their unawareness on cataract, a phenomenon similarly noted in many other countries such as China, Pakistan, India and countries in Latin America.²⁻⁴ Cataract is a painless gradual loss of vision, and many will not present themselves even to the easily accessible primary care clinic in the community⁵ unless troublesome problems such as pain or discomfort occur.⁶

Primary care is the frontline and backbone in enhancing equity and efficiency in healthcare systems.⁷ In Malaysia, the public can easily access the Ministry of Health (MOH) primary care clinics for general health assessment and treatment. It is the first step for every potential cataract patient to pursue appropriate eye consultation in relation to their poor visual status.⁸ Patients with significant eye disease requiring specialist care will be referred to the nearest district or state hospital with ophthalmology service for secondary-level treatment.⁵ It is obvious that most patients will need the earliest identification, effective counselling and an efficient referral system from the primary care providers to access the specialist service for further management.⁹

In the context of this study, barriers to cataract surgery were defined as obstacles that prevent communication or progress to attain and undergo cataract surgery.³ Any form of barrier at the primary care level will prevent them from attaining further treatment for visual recovery achievable only by cataract extraction surgery. Some of the barriers identified to the primary care level in other countries include lack of standard care procedure, ineffective primary eye care interventions and insufficient research or failure to apply related research findings for future planning.⁹

In the low and middle-income African countries, one of the major barrier noted was poor communication with patients and their family members due to language differences or misunderstanding.¹⁰ In Pakistan, ineffective approach to patient's education resulted in delayed presentation, poor

surgical uptake and noncompliance to follow up.³ Inadequate effective continuous medical education among the primary care providers resulted in poor knowledge and inefficient healthcare practitioners causing the delay in diagnosis and subsequent care.³ Denial of treatment by providers was reported as a form of barrier in Peru but not in other states of Latin America.⁴ In the NES2, only 5.3% of patients identified having cataract blindness was denied surgical treatment by providers in the Northern zone.¹ In order to reduce the prevalence of cataract blindness in Malaysia, we need to increase the cataract surgery uptake by identifying the barriers at the primary care level.

Thus, the objective of this study was to explore the barriers at the level of primary care services to cataract surgery from the perspective of patients with severe cataract blindness. The findings can benefit future healthcare planning and policies regarding the eye care delivery system. This was a qualitative study employing the interpretative phenomenological analysis (IPA) approach more renowned in health psychology research. It was our methodology of choice since it focuses on the participant's in-depth description of their experiences and understanding of the state of progressive blindness due to cataract.¹¹ Predicting pre-existing theoretical preconceptions was not the prime focus of this study, thus the results were unrestricted and allowed wide possibilities of under-expected findings. It was meant to be exploratory to answer unspecific research questions in contrary to the pre-defined parameters of a quantitative research.¹¹ The only research published in the field of ophthalmology utilising the same approach was a study on patients with age-related macular degeneration.¹²

MATERIALS AND METHODS

This study identified participants among those with severe cataract blindness in both eyes confirmed by ophthalmologists in MOH hospitals in the Eastern zone of Peninsular Malaysia, i.e., the states of Terengganu, Kelantan and Pahang. The sample selection was purposive for those who had severe cataract blindness with the best corrected visual acuity of worse than 3/60 in the better eye, fluent in English or Malay, and above 50 years old. Patients who had difficulty to speak or denied cataract surgery because of their significant systemic and ocular co-morbidity were excluded. The summary of the participants is listed in Table I.

Following the recommendation of Plummer-D'Amato,¹³ a step-by-step, in-depth interview was conducted in the participants' homes. Only one person, i.e., the first author was involved in conducting all interviews using a standardised guided interview format enhanced by a pilot study performed on three participants. Written consent was obtained from every participant to interview them with or without their immediate relatives. All interviews conducted in local Malay dialect in their own home setting and surrounding, facilitated excellent rapport and good responses to generate accurate actual life situation analysis through the 60 to 90 minute face-to-face encounters. With the participant's special permission, digital audio-recorder was used to record all the interview sessions. The recordings were typed verbatim and the transcripts were analysed by two independent researchers using the six stages of data analysis designed by Smith, Flowers and Larkin.¹⁴ NVivo software version 8.0 facilitated

the coding and analysis of the transcripts and for instant identification of the relevant quotes.

The IPA approach involved data familiarisation and emersion, followed by validation process of the text and its theoretical comment by the first and second author independently and finally verified by matching the situational analysis of the participant. The initial themes identified were listed and further analysed to develop connections between them for further in-depth understanding before interviewing the next participant. We adhered to the similar steps in the analysis process of every transcript to identify identical or new themes. Excluding the initial three participants for the pilot study, the total number of participants selected for the actual study was eleven. It was determined by identifying the last participant as the end-point for this study when the analysis of his or her transcript did not provide any additional new theme, which indicated the achievement of data saturation.

The identified themes across all the analysed transcripts were merged, classified and finally constructed into main themes and subthemes. We selected some of the relevant quotes coded to represent the final themes. The third and fourth authors acted as independent researchers verified every identified theme and resolved any conflict of opinions aroused at every step of the analysis. The whole process of verbatim transcription, analysis and identification of themes was done in the Malay language. The translation of relevant themes and quotes to English was done during the preparation of the manuscript with the unanimous agreement of all the authors. The ethical approval was obtained from the UniSZA Human Research Ethics Committee (UHREC) with reference number UniSZA.C/1/UHREC/628-1(64) dated 2 May 2016. This study was also registered with the National Medical Research Registry (NMRR) with the research identification number 30360.

RESULTS

The first main theme identified was nondisclosure of their visual problems, primarily because of their commitments to their personal and family needs in daily living. Three subthemes under the first main theme were their belated needs for better sight, delayed awareness of their visual status and guarding their social stigma by keeping secret their visual problem from family members or primary care providers. The second main theme was the patient-provider-related issues. The subthemes include miscommunication and the delay in referral to specialist care level. The summary of the identified themes is in Table II

Main Theme 1: Nondisclosure of visual problem

This theme explains why they believe surgery was not required which led to the delay in disclosure of their visual problem to family members or primary care providers. They were committed to their daily living activities to sustain their personal and family needs. Their main concerns were only to maintain the livelihood of their family members until they forgot to care of their own health and wellbeing. They avoid causing disruption to their family's daily routines by not revealing their visual problems

Table I: Characteristics of all eleven participants identified by pseudoname

Name	Gender	Age	Visual Acuity		Marital status	Location	Socio-economic status
			Right	Left			
Yah	F	59	CF	CF	Married	Besut, Terengganu	Good Own house, car and land
Ismail	M	54	CF	CF	Married	Besut, Terengganu	Very poor Stay in house rendered by government
Khatijah	F	73	PL	HM	Widow	Kemaman, Terengganu	Good Stay with daughter's family. Own a house
Hasmah	F	63	PL	HM	Widow	Kemaman, Terengganu	Good Alternately stay with mother and daughter
Mak Tok	F	72	HM	PL	Widow	Kok Lanas, Kelantan	Good Stay with adult child who was a teacher
Riah	F	51	CF	2/60	Divorcee	Tumpat, Kelantan	Moderate Stay with her daughter
Fatimah	F	72	CF	CF	Widow	Temangan, Kelantan	Good Lives in own house with son to look after her
Ani	F	51	CF	CF	Married	Kuala Krai, Kelantan	Poor Lives in surrogate house. Husband has no fixed income
Jah	F	72	HM	2/60	Widow	Kuala Krai, Kelantan	Moderate Lives on social welfare stipends with physically handicapped son
Hamzah	M	81	1/60	2/60	Married	Bukit Ibam, Pahang	Good Has two houses and fruit orchard
Tok Cun	F	70	1/60	HM	Widow	Rompin, Pahang	Moderate Stay with her daughter's family. Own a house in Jerantut Pahang.

Legend: F: Female; M: Male; CF: Counting finger; HM: Hand movement; PL: Perception of light

Table II: The identified themes classified into main themes and subthemes

Main Theme	Subtheme
Nondisclosure of visual problem	Belated needs for better sight Delayed awareness of their visual status
Patient-provider related issues	Social stigma Miscommunication Delay in referral

Belated needs for better sight

Most of our participants disregard the issue of them having cataract as long as they were able to perform their daily routine such as cooking and preparing meals for their family, doing house chores such as sweeping, spend sightseeing with the family, and gardening. Their poor eyesight did not stop them from continuing their daily routine even though the results were imperfect. The difficulties experienced while doing their routine activities were resolved in various ways based on their creativity and capability. Tok Cun was an example among them who obliged to help her daughter to cook rice and prepare meals whenever required.

"I am able to cook rice using the rice cooker. If I am cooking curry, I will ask my grandchild to come and tell me either it's cooked or not. Sometime, when I turned on the gas slowly, I could see the red flame. I could recognise the new gas by looking at the green flame." (Tok Cun; 1/60, HM, Pahang)

Delayed awareness of their visual status

Madam Hasmah had severe blindness in one eye due to cataract, was fully contented with the better vision in the other eye at the early stage to manage her daily life activities. She was unaware and did not express her eye problem to the doctor in the local health clinic even though she could easily access the clinic regularly for her other ailments.

"I don't know about my eyes. I have hypertension, diabetes, heart attack and always got flu. I have been going regularly to the Klinik Kesihatan nearby for my medication. I had no intention to ask the doctor about my eyes even if I can barely see. Can they check my eyes too?" (Hasmah; PL, HM, Terengganu)

Social stigma

To some of the participants, the social stigma of being labelled as visually handicapped was a major issue within the family and community. They tried their best to perform their physical activities and daily routines to avoid being discovered by others.

Researcher: When you went for your treatment for asthma, did you tell the doctor about your eye problem?

Mak Tok: No...no...no...(grinning and respondent seems shy).

Respondent's grandchild: No one knows that she cannot see very well.

Researcher: May I know why?

Mak Tok: I don't know. I don't want to tell anyone (smiling). I wanted to keep my eye problem a secret but they have just found out about it. I don't want them to worry about me. (Mak Tok; HM, PL, Kelantan)

Main Theme 2: Patient-provider-related issue

The patient-provider-related issues refer to the problems experienced by the participants while dealing with the providers at primary care level. Patients with cataract will ultimately reach the situation when their poor vision becomes more obvious to themselves and later to others. They were hesitated to inform the primary care practitioners until their problem goes unnoticed or were not taken seriously without further actions. It was only in the later stage, when their difficulties get more noticeable or when they were inevitably forced to inform the primary care practitioner. However, participants did highlight the issues of miscommunication and the delay in referral to the specialist for further management.

Miscommunication

During her follow up for hypertension, Jah's initial complaint was ignored by the doctor. It was after Jah's daughter conveyed the problems, only then the doctor examined her and taken further actions.

"I have told the doctor at the clinic regarding my eye while attending my blood pressure check-up. But the doctor ignored my complaint about my eye problem. On the next visit for my high blood pressure, my daughter told the doctor about my eye, but the doctor also ignored it. Finally, on the subsequent visit when my sight became much worse, only then the doctor wrote a referral letter to the eye specialist. My right eye vision could barely see and I was depending on my left eye a lot." (Jah; HM, 2/60, Kelantan)

Delayed in referral

The current policy required all patients suspected or diagnosed as having a cataract in the MOH to be seen by an eye specialist for appropriate consultation, confirmation of diagnosis, decision making and planning of surgery. The bureaucracy involved throughout this process was noted by Hasmah as one of the main deterrents she encountered.

"I told the doctor about my eye problem in 2015 (2 years ago). The doctor also has checked my eyes, told me about cataract and the need to see an eye specialist. Unfortunately, the nurse that handled the referral letter went for a course and forgotten about it. But recently, that nurse was working and she managed to handle my referral letter to Kemaman Hospital. She had to handle everything so, when she went to the course, there was no one else that replace her." (Hasmah; PL, HM, Terengganu)

DISCUSSION

The prime concerns of the participants were their ability to perform activities of daily living (ADL) in their everyday lives without assistance from family, relatives or neighbours. Most of the participants did not indicate any difficulty in performing their ADLs in spite of reduced vision at an early stage. They were satisfied as long as they could still contribute to the needs of all their family members, able to move about, and continue with their interpersonal cooperation to fulfil all their basic living needs. They could still perform their ADLs as a housewife or pensioner without much expectation for better vision. In a qualitative study done in rural South Africa, 30% of the participants did not consider themselves as severely handicapped as they could still see, continue doing work with their hands, able to get dressed and walk without assistance, and perceived themselves as not a great burden to their family.¹⁵

The ability to perform house chores indicates that elderly people voluntarily take responsibility to reduce the burden among adult child in providing a better life to their family as highlighted by a study on the practice of interdependence among Malay elderly in the community in Malaysia.¹⁶ However, in China, decreased vision associated with increased cataract maturity negatively affects the performance of daily activities among cataract patients.^{17,18} Thus, the visual requirement for ADL was very subjective and can be measured by the patients' life satisfaction and their urgency for surgery. However, we have to stick to the standard visual acuity measurement used to assess visual impairment in the current practice. The elderly people should not wait until they are completely unable to perform their ADL. Improving the sensitivity of close family members regarding the visual status of the elderly people and the need for better vision by earlier surgery is warranted. This will allow them to improve their quality of life (QoL) by sustaining their best physical performance before the inevitable worsening towards severe blindness.⁸

Keeping visual problem as a secret from family members and healthcare personnel was one phenomenon seen among our study participants. They are worried on the consequences of anyone knowing about their problems such as having the stigma of being visually handicapped, disrupting their commitments to the needs of the family or having to go for further treatment or surgery. They adapt to the poor vision in one eye at the early stage and only disclose then the opposite eye had deteriorated beyond tolerance. In spite of their easy access to primary care, they utilised these services only for their routine follow up such as for asthma, hypertension and diabetes mellitus but disregard their visual problem. Otherwise, the primary care clinic visits were primarily symptom led, such as for pain. Previous and continuing relationship with the healthcare personnel made patients feel more comfortable and encouraged them to access the healthcare.⁵ Continuing good relationship can certainly alleviate the refusal attitude to disclose their visual problems among patients who are having painless progressive loss of vision due to cataract. All healthcare personnel are suggested to be more proactive and alert to address this issue more effectively.

A social stigma is a form of barrier to earlier cataract surgery which needs special attention and way to address it in daily practice among primary care practitioners. The female participants in our study were secretive with their visual deterioration and more apprehensive in inflicting inconveniences to their family. Similarly, in Tanzania, men were more dominant in adopting the "sick role" and more frequently accessed healthcare facilities compared to women who kept silent and try acting as a "normal" person instead of informing their relative for their ailments.¹⁹

The proportion of elderly or geriatric population in Malaysia is increasing as the percentage was 5.2% in 1970, 5.7% in 1990 and 6.3% in the year 2000.²⁰ This figure is expected to increase to 9.8% by the year 2020 among the increasing population of 18.4 million to 33.3 million, an increase of 80%.²⁰ Most of the elderly showed their preference in treatment-seeking behaviour for hypertension (90%) and diabetes (92%) as compared to visual problems (20%), dental problems (47%), joint complains (54%) and memory impairment (13%). Although visual problem was reported as the highest problem, only 20% sought treatment in India.²¹

An opportunistic screening by primary care clinic nurses to elicit visual problems during every visit is proposed to overcome this issue. Visual acuity testing is highly recommended as part of the routine check-up for all patients above 50 years old. This measure will certainly worth it, as the NES2 revealed the national prevalence of low vision of 5.5 %, ranging from 4.6 % to 9.4 % in all zones.¹ Thus, we strongly advocate routine visual acuity screening, together with the regular assessment for blood-sugar and blood pressure levels, which has been made routine in every clinical setting.

The second main theme describes the patient-provider-related issues namely miscommunication and delayed in referral to specialist care. Indeed, good communication skills, especially in taking time to listen and providing a clear explanation is the kind of communication desired by most patients. Unfortunately, some of our participants revealed that miscommunication is still a major barrier due to the ignorance of doctors in primary health clinic regarding cataract and its surgical treatment. They seem to have lack of confidence in doctors in the health clinics and have more faith in other forms of treatment or opinion given by relatives or friends through the words of mouth. Irfan and colleagues³ highlighted similar issues among the people of Pakistan which proved that patients with lower education level and those with lack of communication between patient and doctor, may delay presentation and subsequently the surgery as well. Geriatric patients have been shown to appreciate doctors who show respect, listen carefully, explain things, give easy-to-understand instructions, and spend enough time with them.²²

The processes in MOH services stated that a referral letter is compulsory in accessing specialist care in the district or general hospitals.²³ Unfortunately, any interruption in the process of care will delay or deter patients in accessing the next step of their healthcare assessment and management. The long waiting time for the referral letter and lack of staff

involved in processing the referral letter was highlighted by some of the participants in the current study. The responsible authority involved in the process of referring patients from the health clinic at the primary care level should be sensitive and maximally efficient in solving this problem.

The delay in referral for treatment and surgery is a common barrier reported in the low- and middle-income countries (LMIC) and has resulted in greater morbidity and mortality problems.¹⁰ Olegunde and colleagues found the combination of the poor referral system and miscommunication between healthcare facilities in LMIC has resulted in delayed care and treatment among patients.¹⁰ Thus, the idea of an electronic referral system from the primary care to the specialists needs to be considered seriously.

The limitation of this study is inherent to all qualitatively designed studies. Specifically, its limited representation of the elderly Malays in Kelantan, Terengganu and Pahang might not be able to represent the whole of Malaysia. Due to the language barrier, all Chinese and Indian patients identified were not fluent enough for the effective conduct of the in-depth interview fundamental in IPA approach. Most of the study participants included were unintentionally from the rural areas and their perspectives could not represent patients from the urban area. Thus, further study is required to address this serious issue regarding the other specific population group in Malaysia.

In conclusion, the barriers to cataract surgery identified at the primary care level in the Eastern zone of Peninsular Malaysia need specific, speedy and appropriate approaches. Targeting the primary care providers might be able to educate and motivate patients for early cataract surgery to prevent blindness. Further improvement in eye health education and promotion and the implementation of routine opportunistic visual acuity screening could propagate awareness of the community and healthcare providers. Strategic eye care delivery system, such as electronic referral could promote earlier and more extensive cataract surgery uptake among elderly patients to improve their vision and prevent severe blindness.

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