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CLINICAL STUDY

Understanding the patient's lived experience of neovascular age-related macular degeneration: a qualitative study

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Abstract

Purpose **In industrialised populations age-related macular degeneration (ARMD) is the leading cause of visual disability of the elderly. Successful new treatment with anti-endothelial growth factors for neovascular-classified ARMD has led to a divergence in treatment and experiences of people ARMD. This study aimed to understand the participant's experience of neovascular ARMD, including ongoing treatment with anti-vascular endothelial growth factor.**

Methods **Twenty-five participants from one clinical site were qualitatively interviewed to elicit their experiences of treatment for neovascular ARMD.**

Results **Two major themes were identified. A life negotiated by neovascular ARMD captures the participants' experience of living with the condition and treatment regime for neovascular ARMD. The second major theme: Uncertainty displayed their appraisal of life, treatment and their perceived future.**

Conclusions **Anxieties concerning the injections, new limitations to lifestyles, and an uncertain future all emerged from the data analysis. However, thankfulness for the treatment, the importance of familiar patterns in treatments and recovery and a guarded optimism also emerged. Knowledge of the experiences, anxieties and concerns of this patient population can be used to inform clinical practice and lead to patient-centred care.**

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Introduction

In industrialised nations age-related macular degeneration (ARMD) is widely cited as the dominant cause of vision impairment or blindness in 50% of legally blind older adults.[1,2] The Australian incidence of ARMD is consistent with that reported internationally[3,4] and has the congruent nomenclature of ARMD, broadly divided into either geographic ARMD, 'dry' or neovascular ARMD, also known as 'wet' ARMD. In the past, geographic ARMD was considered largely untreatable,[5,6] while neovascular ARMD treatment had demonstrated very limited success. The distinction between the two classifications of ARMD is relevant for prognostic purposes, including expected disease progression and potential visual disability. Recently, an increasing divergence between the two classifications has become evident, resulting from the development of anti-vascular endothelial growth factors (anti-VEGF) as a successful treatment for neovascular ARMD[7–10] in comparison with a continuing lack of successful treatment for geographic ARMD.[11] This divergence is not limited to pathophysiology and treatment of ARMD, but extends to differences in patient experiences of ARMD,[12] including differences in treatment outcomes, saving of sight, and invasiveness of treatment regimes.

The literature concerned with ARMD is extensive, with the vast majority of studies reporting on physical aspects—such as treatment options, incidence, and progression of disease.[13–15] Such quantitative evidence is vital for the ongoing development of successful treatment for ARMD. However, the voice of patients who undergo such interventions that are at the core of most reported studies, is not often heard and knowledge of their experiences

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and the sense they make of this illness is often lost in the technical and quantifiable worlds of quantitative research. In the past qualitative explorations of people's experience of ARMD, generally reported on people with end-stage ARMD, often after significant vision has been lost.[16,17,18] Such studies predated the widespread use of anti-VEGF treatments for neovascular ARMD and were unable to elucidate experiences of people for whom vision loss could be avoided or limited.

In 2013 Burton *et al*,[19] studied people's experience of treatments for neovascular ARMD, which has shed valuable knowledge on participant issues related to information requirements, communication difficulties, and alluded to feelings of uncertainty regarding vision and its potential loss.[19] In line with qualitative research methodology, the study was limited to seven participants from one healthcare institution and can be considered as a small but important first step towards developing a body of experiential knowledge of treatment for neovascular ARMD. Boyle *et al*[20] conducted a systematic review of 10 studies concerned with treatment for neovascular ARMD and this review has added to our understanding of injection experiences, pain, discomfort, and fears experienced by people undergoing treatment. However, the literature reviewed by Boyle *et al* was dominated by quantitative research methods with only two included papers stating the use of qualitative research methods. It is well known that quantitative research is limited in its capacity to capture what is meaningful and important to people experiencing healthcare treatments.[20]

Experiential patient evidence is a cornerstone of patient-centred care[21] and it is well established that patients' views and experiences of diseases and treatment have an important role in the planning and provision of patient care.[22] Given the rapid uptake and success of anti-VGEF treatment in neovascular ARMD, knowledge of patients' experiences of this ongoing and sight-saving treatment will add and complement current understanding of this widespread and much feared condition. This paper reports on a study of 25 people's experience of treatment for neovascular ARMD, and will add to the emerging body of experiential knowledge of this condition. This study aims to expand on what is known to be meaningful and important to people as they progressed through a rigorous treatment process where visual disability, always a threat, can now, in many cases, be kept at bay.

Aim of the study

This study aimed to understand the patients experience of neovascular ARMD, including ongoing treatment with anti-VEGF, with the intention of informing clinical practice.

Materials and methods

The study reported here was guided by an interpretive-phenomenological research tradition, which focused the study towards understanding and interpretation of experiences within the everyday social context.[21] Understanding the phenomena required collection and recording of individual participant experiences, and provided an opportunity to study the phenomena from 'inside' subjective experiences.[22] Analysis, leading to interpretation, required the researchers to engage the concepts of; emergent themes, where coded data were clustered into commonalities and later grouped into themes; reflexivity—questioning 'what is going on here' in the data; and dialectical reasoning where emerging themes were aligned with existing theory or knowledge that promoted a way of 'thinking further' about the phenomena.[13]

Participants and recruitment

Sampling in this qualitative research embraced non probability methods where participants who have experienced the phenomena of issue can provide rich and detailed data.[14] All participants of the study had received a diagnosis of neovascular ARMD and were receiving treatment with anti-VEGF in at least one eye on a regular basis. Potential participants were identified from clinical records of a South Australian Tertiary Public Hospital and all participants received their treatment without co-payment fees. Potential participants were provided with information regarding the study, and those who expressed an interest in the study were later contacted by phone by the first researcher who was not involved in clinical care of the participants.

Data collection

Twenty-five people were purposively recruited for in-depth, unstructured interviews. Unstructured interviewing techniques facilitate 'seeing and hearing' the multiple views and experiences of people,[22] and was considered the most appropriate method of data collection for this study. Single face to face interviews were conducted that commenced with the question 'tell me of your experiences of ARMD and the treatment you are receiving?' Interviews lasted between 30 and 90 min and ended when the participant had no further information to share. All interviews were audio-recorded and later transcribed verbatim. Further data were collected from the medical records of the participants and included demographic details and specific information concerned with visual acuity and disease diagnosis. At the commencement of the study, a focus group of the

nursing staff that cared for the people experiencing anti-VEGF treatments was conducted. This focus group provided background information regarding anti-VEGFs treatment from the perspective of clinical staff. Using more than one source of information strengthens confidence in the conclusions drawn from the findings of the study.[15]

Thematic analysis

All data were analysed using Saldana's (2013) codes to theory model, where initial coded segments were clustered into categories that led to theme development.[23,24] Analysis commenced after the first five interviews and was consistent with constant comparison technique where new data was examined in light of the emerging themes. The use of constant comparison techniques enhanced the 'fit' between data and developing themes and added to the trustworthiness of the findings. Data collection were ceased once concept saturation was reached, where no new codes or themes emerged from the data.[24] QSR Nvivo 10 software (QSR, International, Doncaster, VIC, Australia) assisted with the initial coding of the data.

Statement of ethics

The conduct of this study conformed to the research methods and actions approved by the Southern Adelaide Clinical Human Research Ethics Committee, in application number 164.13 2013. All participants gave written consent for their inclusion, and were informed of their right to withdraw at any time. An assurance of the confidentiality and anonymity of the study was provided to all participants. The moral principles of beneficence, respect for human dignity, justice, and informed consent[25] were addressed and upheld throughout the conduct of this study.

Results

Demographics and details

Thirteen female and 12 male participants aged between 67 and 90 years of age were recruited to this study (see Table 1). All participants had a diagnosis of neovascular ARMD in at least one eye and were undergoing an 'as required' management strategy, where anti-VEGF treatment was decided on the basis of their Optical Coherence Tomography (OCT) results, and administered at between 4–8 weekly intervals. Participants received injections of one of the three types of anti-VEGF either; bevacizumab (Avastin; Roche, Dee Why, NSW, Australia); ranibizumab (Lucentis; Novartis, North Ryde, NSW, Australia), or aflibercept (Eylea; Bayer AG, Pymble, NSW, Australia). During the data collection time frame, the drug of choice was changed for a small number of participants depending on the treating ophthalmologist's preference and clinical indication. Prior to injection, participants received two drops of 0.5% amethocaine hydrochloride (Tetracaine; Bausch and Lomb, Macquarie Park, NSW, Australia), and a further anaesthetic agent was used as sub conjunctival injection of 0.2 ml of 2% lignocaine. All injections were conducted in the outpatient consulting rooms of the Eye Clinic and used a sterile technique that include injection site preparation with one drop of half strength 5% Povidone–iodine (Betadine; Pfizer, West Ryde, NSW, Australia). Access to the injection site was aided by the use of an eyelid speculum and the intra-vitreal anti-VEGF was administered with a 30G needle. Post injection, the eye was routinely irrigated with 0.9% normal saline to flush out residual betadine and the previous practice of antibiotic drops and covering with eye pad had ceased at the commencement of the study. Participants were discharged immediately following the injection and the presence of a carer on the journey home was not stipulated.

Participants duration of ARMD ranged from a few months to many years (see Table 1), and a few participants had experienced previous treatments that included photodynamic or laser therapy. The two major themes identified from the narratives of the participants included: 'A Life negotiated by neovascular ARMD'; and 'Uncertainty'. The development of themes from coded narrative segments is represented in Figure 1, where it can be seen how coded segments were coalesced into larger sub-themes and then into two major themes. Exemplars of the themes that are participants words verbatim can be followed in Table 2, and these findings will be discussed in detail under the two major theme headings.

A life negotiated by neovascular ARMD

A diagnosis of neovascular ARMD that required regular ongoing anti-VEGF injection was for most participants a life changing event that evoked a range of feelings and fears, from high anxiety (quote 1) to pragmatic acceptance (quote 2). Following diagnosis and knowledge of treatment options relief was expressed by many participants that the condition could be treated (quote 3), but these comments were closely followed by apprehension at the thought of having a 'needle' into the eye (quotes 4 and 5). The experience of the first injection was memorable for most participants as either very painful (quotes 6 and 7) or being better than they had anticipated (quote 8). The first injection experience was influential in participants consideration of ongoing treatment (quote 9) and a few participants had friends or

Table 1 Participants demographics

Participant	*Age*	*Gender*	*Diagnosis*	*Visual acuity*	*Years of treatment*
1	87	Female	L = ARMD-wet R = Cataract	L 6/6R 6/15	9 months
2	82	Female	L = ARMD-dry R = ARMD-wet	L 6/30 R6/76	5 years
3	73	Male	L = ARMD-wet R = ARMD-wet	L 6/9.5R /9.5	9 years
4	80	Female	L = ARMD-wet R = ARMD-dry	L 6./7.6R 6/60	10 years
5	84	Female	L = ARMD-dry R = ARMD-wet	L 6/60R 6/12	8 years
6	84	Female	L = ARMD-wet R = ARMD-dry	L 6/24R 6/120	>10 years
7	81	Female	L = ARMD-wet R = ARMD-dry	L 6/12R 6/24	2 years
8	86	Female	L = ARMD-wet R = ARMD-dry	L 6/15R 6/15	2–3 years
9	70	Male	L = ARMD-wet R = ARMD-wet	L 6/15R 6/15	<1 year
10	88	Male	L = ARMD-wet R = BRVO	L 6/15R 6/24	3 years
11	74	Male	L = ARMD-wet R = ARMD-dry	L 6/12R 6/18	2–3 years
12	88	Male	L = ARMD-wet R = ARMD-dry	L 6/19R 6/24	2–3 years
13	87	Male	L = ARMD-wet R = CSMO	L6/19R CF	3 years
14	92	Male	L = ARMD-wet R = PEO	L 6/12R CF	9 years
15	76	Male	L = ARMD-wet R = ARMD-wet	L 6/12R 6 /18	<6 months
16	83	Male	L = ARMD-wet R = ARMD-wet	L 6/12R 6/12	3–4 years
17	73	Female	L = ARMD-wet R = ARMD-wet	L 6/7.6R 6/6	>5 years
18	89	Female	L = ARMD-wet R = ARMD-dry	L 6/12R CF	
19	83	Male	L = NAD R = ARMD-wet	L 6/9.5R 6/15	6 years
20	77	Female	L = RD R = ARMD-wet	L 6/120R 6/15	2 years
21	89	Female	L = Cataract R = ARMD-wet	L 6/15R 6/19	4–5 years
22	76	Male	L = ARMD-wet R = MH	L 6/12R 6/60	3 years
23	90	Male	L = ARMD-wet R = Disciform scar	L 6/24R CF	>10 years
24	91	Female	R = Amblyopia L = ARMD-wet	L6/36R 6/12	2–3 years
25	84	Female	L = ARMD-dry R = ARMD-wet	L 6/60R 6/12	3–4 years

family members who had chosen not to continue with treatment due to the difficulties of the injection (quote 10). Subsequent treatments appeared to be less problematic and many participants found that positive experiences of the process helped them to cope well with the injections (quotes 11 and 12). As participants settled into an ongoing treatment regime of between 4–8 weekly anti-VEGF injections, they developed familiarity with the processes and interventions of this disease management process (quote 13), although the injection continued to be a source of anxiety, particularly when an unknown clinician was to give the injection (quote 14).

The context of this study was an Australian Public hospital clinic that was also an ophthalmology training

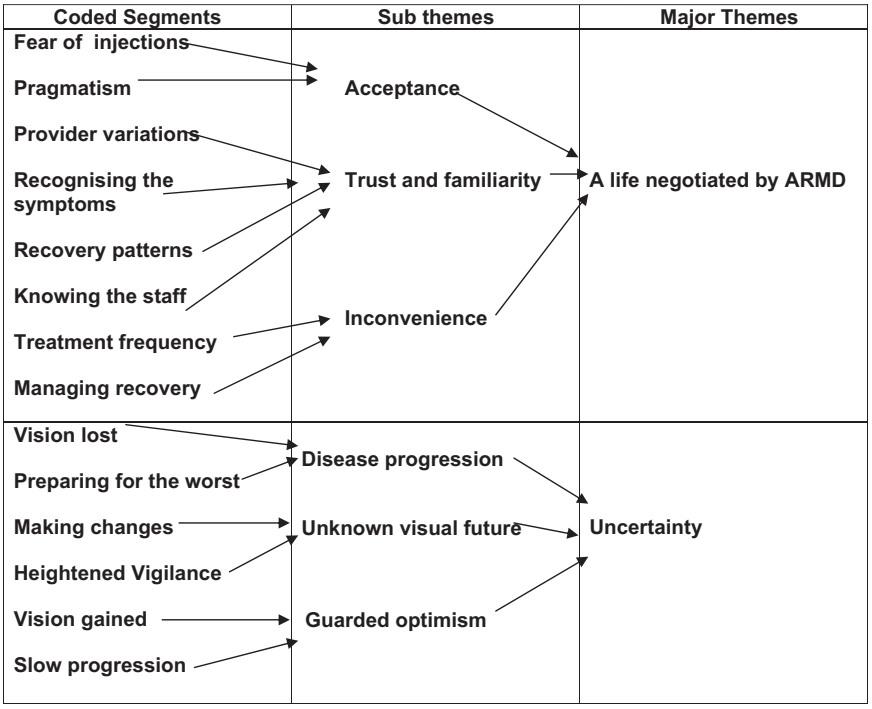

Figure 1 The development of themes from coded narrative segments.

venue. As such there was a regular rotation of training ophthalmic specialists who were often the providers of treatments. The skill and capacity of trainees to provide pain-free injections was commented on by participants (quotes 15 and 16), and influenced participants experiences. Reassurance and comfort was found by participants in familiarity with not only the procedure but also the provider of the treatment (quote 17). When changes occurred, participants trust in familiar processes and providers was challenged and often led to deep anxiety (quotes 18 and 19). One participant described a negative experience of injection, given by an unfamiliar ophthalmologist, which prompted him to refuse to have treatment unless given by a known and trusted ophthalmologist (quote 20). Despite occasional problems with injections, participants expressed a belief that they were receiving an excellent service that was maintaining their sight for as long as possible.

Changes to the clinician giving the injection and variations to the treatment processes were the subjects of participant comments and changes in these treatment aspects were often linked by participants to recovery difficulties. Variations included small unexpected changes such as: use (or not) of topical anaesthesia (quote 21), techniques of betadine removal (quote 22), or methods in removal of the speculum (quote 23). Planned changes to the process that included, stopping of antimicrobial drops (quote 24) and a lack of eye pad after the procedure (quote 25), were also linked to recovery difficulties. However, over time and when communicated well participants felt that many of the changes, once they became familiar with the new methods, had improved the overall experience (quote 26).

As participants developed familiarity with the injection process, they also developed patterns of behaviour that facilitated their recuperation (quotes 27 and 28). Being aware of visual disturbances and discomfort (quotes 29–31) that usually occurred after the injection, many participants spent time resting or sleeping while waiting for the anaesthetic to wear off and their vision to return (quotes 27–30). All participants described recovery behaviours that limited daily activities, such as driving, watching TV or reading, from a few hours to a few days. When recovery progressed in a known pattern participants were comfortable, it was when unexpected symptoms occurred such as, conjunctival haemorrhage, intra ocular bleeding, and exacerbated pain occurred that participants became very anxious (quote 30). Very few participants reported seeking advice from the ophthalmic clinic when difficulties arose, usually choosing to wait for symptoms to subside. Participants endured the ongoing treatment and surveillance for disease progression that for many, successfully limited loss of vision (quote 32). Very few participants expressed a desire to stop treatment, despite the rigours while vision was being maintained (quote 33). Participants' endurance of invasive treatments was underpinned by a pervasive fear of blindness (quote 34), and treatment experiences were considered by many

Table 2 Participant quotes

Theme	*Illustrative quotes*
A life negotiated by neovascular ARMD	1. I freaked a bit when they told me that I had macular degeneration (Pt 3)
	2. I'm quite philosophical about it, I won't like it., but a lot of people in this world have got far worse than what I've got (Pt 17)
	3. I'm grateful that it was picked up early and I'm still able to see quite well (Pt 7)
	4. When you find out about it, it's… it's a little bit of apprehension there. They are going to stick a needle in your eye after all (Pt 22)
	5. Maybe it's the thought of having a needle poked in your eye. Um... certainly a lot of er... mental trauma, when you're just thinking about it. (Pt 9)
	6. the first injection was … was a bit painful, and also I was frightened (Pt 14)
	7. It was really painful, unbelievably painful [the first injection] (Pt 9)
	8. I mean it's the thought more than anything, (Pt 1)
	9. I nearly didn't go back to have any more. I felt that bad about it. (Pt 3)
	10. I've got a friend who has macular, and she had it done once and wouldn't go back (Pt 3).
	11. you get used to them after a while (Pt 10)
	12. If it's done properly … you don't feel it (Pt 22)
	13. I tootle along, and I know exactly what's going to happen and it doesn't bother me at all. (Pt 8)
	14. I feel a bit uptight because some one is going to stick a needle in my eye and you don't get the same doctor every time (Pt 11)
	15. maybe they're just not as experienced, they banged the needle in and, you know, you really… makes you jump (Pt 22)
	16. some of them have got the knack [pain free injection] and some of them have not (Pt 4)
	17. in particular the doctor himself … he was just fantastic … he reassured you, and made you feel comfortable (Pt 13)
	18. Somebody that you've never had, you think, oh, I hope they know what they're doing. It's my eyes they're playing with, you know (Pt 5)
	19. They suddenly decide that they're going to change the routine away from the way I know it works … it was scary (Pt 3)'
	20. I vowed that I wouldn't have another one, if Dr… didn't do it and I had to had to have him [(unknown Dr] (Pt 12),
	21. I don't know how many he put in, but it was a huge number…[anaesthetic drops] I couldn't blink… my eye was open all of the time by the time I got home, it had dried out terribly (Pt 3)
	22. I'm sure it was the Betadine that wasn't washed out correctly (Pt 1)
	23. when he took the clip out, he obviously just lightly scratched my eye (Pt 3)
	24. we didn't get given any after-drops, and my eye was very dry (Pt 7)
	25. the procedure was different,... previously I'd leave the hospital firstly with a bandage over it. Now I leave the hospital with nothing [eye bandage] on (Pt 3)
	26. there's been some improvements here, that they've made (Pt 16)
	27. If I go there, I know I'm going to get an anaesthetic in the eye, and I'm going to get the injection, and... and I'm going to be unable to see clearly for a number of hours. I can come home, I can put… just relax and when it comes back, then I'm back to normal (Pt 7)
	28. Well I don't do anything. Once I come home from the hospital that's it, that's my day finished. (Pt 1)
	29. it's very uncomfortable for the first day (Pt 1)
	30. Not painful, but I can't see very well (Pt 10)
	31. 'Now I've got … this great black spot going around everywhere… oh God, what's going on … I've never experienced it before … when I woke up I was in excruciating pain in this eye … there seemed to be something wrong (Pt 3)
	32. I can see now with this one. Before I couldn't see anything at all … my sight has improved quite dramatically (Pt 4)';
	33. As long as I'm happy with my sight as it is, and if they say come back in another three months or come back in six months or whatever it might be, then I'll be happy to do that (Pt 23)
	34. I'd just want to lay down and die if that happens to me (Pt 25)
	35. truthfully the needle in the eye is nothing in comparison to the thought of going blind. (Pt 7)
Uncertainty	36. I mean it's got to be done. It doesn't change your life but it changes your lifestyle (Pt 4)
	37. It's more of an aggravation rather than anything else, to have to go' … [and have regular injections] or a feeling of inconvenience (Pt 1)
	38. you gear your lifestyle around it … if we were wanting to go somewhere you just can't go because of it' [the treatment appointment (Pt 7)
	39. We used to go away for the whole winter, so we couldn't any more … we just altered our lifestyle to suit (Pt 22)
	40. It seemed to put an end to lots of things in life, you know (Pt 17).

Table 2. (Continued)

Theme	*Illustrative quotes*
	41. they did stretch it out an extra week. We did a cruise last year, so yes, they're very obliging (Pt 7) 42. and I thought it was age, everybody's eyesight deteriorates with age (Pt 25) 43. they could deteriorate tomorrow, who knows … you don't know….They say they can't cure it, but they were hoping to hold (Pt 21) 44. I can see now with this one. Before I couldn't see anything at all (Pt 14) 45. my sight has improved quite dramatically (Pt 3) 46. if I hadn't had any treatment … I would be almost … blind by now (Pt 5) 47. my left eye now has er... can't have any more treatment, it's not much good at all now (Pt 2) 48. when they said I had it in the in the right eye as well … that was a little bit scary (Pt 3)' 49. the injection doesn't help everybody, well maybe they don't help me (Pt 14) 50. I'll go blind. Do I have a choice?' 'No … I'm quite philosophical about it. I won't like it … and I'll miss certain things but can I do anything about it? No (Pt 19) 51. It's an acceptance that it has to be done. It's either that or the macular degeneration will continue (Pt 13).

in light of an ongoing threat of blindness and thus pragmatically accepted (quote 35). Reported by a number of participants was the influence of the frequent treatments on their lifestyle (quote 36).

Many participants felt inconvenienced by the need to structure their lives around appointments (quote 37), and subsequently adopted lifestyle modifications that ranged from limitations to a planned day event (quote 38) to constraints to a way of life that they had previously pursued and valued such as extended travel during the winter time (quote 39). Participants who were active and wanted to engage in many leisure activities described sadness at the loss of enjoyment of life that occurred as a result of the treatment regime and vision limitations (quote 40). Ameliorating the inconvenience felt by participants was the flexibility of the healthcare facility when possible in in booking appointments around the activities and needs of participants and was clearly valued by participants (quote 41). All of the participants of this study were over 70 years of age and lived with a degree of uncertainty that arises with aging. Many felt that diminishing vision was an inevitable fact of the aging process (quote 42). However, an ongoing and real threat of blindness based on the knowledge that treatment was not a cure (quote 43) coupled with anxiety of the treatments processes added a further level of uncertainty to participants lives. These aspects of the participants' experience of neovascular ARMD led to development of the second theme of this study—Uncertainty.

Uncertainty

Many of the participants of this study experienced a significant halt to disease progression, and for some an improvement in vision occurred (quotes 44–46). However, optimism felt by participants was moderated by the knowledge that treatment could fail at any time (quote 43) and such a failure was the experience of a few participants (quote 47). Where neovascular ARMD was unilateral participants expressed feelings of relief that the disease was under control and that should progression occur, then they still had the sight of one good eye. However, changes of disease patterns from unilateral to bilateral, which occurred for a number of participants added a heightened anxiety surrounding future vision (quote 48). A number of participants experienced treatment failure with further loss of vision and their words were underpinned by sadness and fear of encroaching visual disability (quotes 49 and 50): All participants knew the 'management not cure' status of anti-VEGF treatment and despite reported treatment successes concerns for their future were voiced. Participants dealt with the threat of visual disability in different ways. Some believed that they could take a loss of vision in their stride and get on with living as best they could. In contrast, others were fearful of treatment failure and the consequence of visual disability and an associated loss of lifestyle. Almost all participants of this study expressed at some time during their interview an ongoing hope that treatment would continue to work and that as long as they could maintain their current vision they would continue with treatments (57). Thus an added uncertainty in regard to vision prognosis coupled with treatment issues previously described contributed to a pervasive sense of uncertainty in the lived experience of participants with neovascular ARMD.

Discussion

The findings of this study have illuminated the participant's experience of neovascular ARMD and treatment they received of regular anti-VEGF injections. Concurring with reported high levels of treatment compliance[23] participants of this study continued with the treatment even when experiences of pain or discomfort were reported, illuminating a deep association between compliance and fear of blindness.[16,26] A fear of blindness

was pervasive in this study population, and more than one participant felt that death would be preferable to living with the limitations of blindness, which was a finding that resonated with suicide ideation following vision loss described by Casten and Rovner in 2008.[18] Ongoing lifestyle limitations described by the participants of this study were similar to findings of other studies of people with significant vision loss.[27,28] The experience of the anti-VEGF injections for neovascular ARMD had not been studied in detail in the past, and this study has shed light on the burden and anxieties associated with the rigorous and ongoing treatment regime for what is now a chronic lifelong disease.

Conquering fear of the injection process occurred for participants who had uneventful and painless experiences and led them to the belief that it was the thought of the injection rather than the reality that had caused their previous anxiety. However, a single difficult treatment experience reverberated for many participants along the trajectory of their treatment and led to a heightened sensitivity to their believed causative factor. Difficult experiences were clearly linked with circumstances that were unknown or unfamiliar, such as changes to treating clinicians, changes to processes, and variations in recovery events. This finding highlighted the participants need for familiarity as an important element in positive patient experiences. Many participants knew of the true cost of the treatment and were grateful to be receiving this treatment free of charge. However, participants were aware that as Government-funded patients they rarely had a choice in, who provided the treatment at each episode, and changes to treatment processes. Some were philosophical about the apparent lack of control, provided their treatment was not difficult, but others found the uncertainty of an unknown clinician, or treatment change challenging, particularly as they sat in the clinics waiting for treatment by unknown clinicians.

The relationship between the healthcare facility staff and participants was crucial in helping overcome anxieties regarding treatment, recovery, and disease progression. Reassurance, caring communication and feeling supported by known staff members all contributed to participants enduring the rigours of the treatment. Participants accepted that they would need to have treatment for very long periods to help maintain their vision. Although they endured the treatments, there was often an underlying knowledge and fear that treatment could fail and they would slide into visual disability. Looking into an unknown future in regard to vision function elicited divergent responses. The majority of participants were philosophical about the future and were thankful for the sight they had had in the past, or attributed their decline to advancing age. Many made lifestyle adjustments that allowed them to pursue hobbies and interests that accommodated some loss of vision and this helped to foster a positive outlook. Where participants continued to have good responses to anti-VEGF therapy they expressed heartfelt thanks for the treatment being available and that their fear of blindness could be assuaged, although not eliminated.

This small study of 25 participants who were experiencing neovascular ARMD and treatment with anti-VEGF therapy has a number of limitations. In line with qualitative research methodology, the study was confined to a small sample size, which will facilitate transference of the knowledge, but not generalisation. A second limitation is the recruitment of all participants from one healthcare facility within a major Australian metropolitan hospital, which misses patient experiences from other clinical settings. The experiences of people from diverse backgrounds, such as rural patients, non-English speaking people, and Australian Aboriginal populations have not had voice through this research project. However, as a result of this study new knowledge of the experience of neovascular ARMD has emerged. Knowledge of the experiences, anxieties, and concerns of this patient population can be used to inform clinical practice and lead to true patient-centred care. The findings of this study would support changes to practice that address participant issues of continuity of service providers and treatment techniques, management of process changes that enhance patient acceptance of change, recognition of an added uncertainty patients experience, and potential to adopt measure that reduce uncertainty. Finally, the role of uncertainty in the participants experience needs further investigation and has the potential to enhance praxis through linking of theory and practice.

Summary

What was known before

- There is a reported high rate of treatment compliance with invasive treatment regimens for neovascular ARMD.
- Fear of blindness in people with sight threatening conditions has been well documented. Treatment for neovascular ARMD is an invasive and rigorous process.

What this study adds

- This study has shed light on the burden and anxieties associated with the rigorous and ongoing treatment for a chronic sight threatening disease.
- Understanding of the role familarity with processes, people and events have in positive patient experiences of treatment for neovascular ARMD.
- Understanding of an emerging but guarded optimism and its influence on the psychological well-being of participants who experience successful treatment for neovascular ARMD.

Conflict of interest

The authors declare no conflict of interest.

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