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Acceptability of Home Monitoring for Neovascular Age-Related Macular Degeneration Reactivation: A Qualitative Study

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Abstract. This study formed part of a diagnostic test accuracy study to quantify the ability of three index home monitoring (HM) tests (one paper-based and two digital tests) to identify reactivation in Neovascular age-related macular degeneration (nAMD). The aim of the study was to investigate views about acceptability and explore adherence to weekly HM. Semi-structured interviews were held with 98 patients, family members, and healthcare professionals. A thematic approach was used which was informed by theories of technology acceptance. Various factors influenced acceptability including a patient's understanding about the purpose of monitoring. Training and ongoing support were regarded as essential for overcoming unfamiliarity with digital technology. Findings have implications for implementation of digital HM in the care of older people with nAMD and other long-term conditions.

1. Introduction

Age-related macular degeneration (AMD) is a chronic, progressive condition and the commonest cause of vision loss in older adults[1]. Ongoing surveillance is necessary to manage disease activity since nAMD can recur following periods of treatment[2]. Home monitoring (HM), as a form on ongoing disease surveillance, could potentially reduce the frequency of clinic monitoring visits. Mobile Health (mHealth) refers to use of devices including mobile phones, tablet computers or patient monitoring devices to detect and monitor changes in patient's health and illness status[3]. However, views

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about acceptability of HM are unclear. This study formed part of a multi-centre diagnostic test accuracy cohort study (The MONARCH Study)[4] which quantified the ability of three, non-invasive index HM tests to detect reactivation of nAMD, in comparison to a reference diagnosis of reactivation in a usual care nAMD monitoring clinic. The index tests were the paper-based KeepSight Journal (KSJ), and two digital tests, the MyVisionTrack® (mVT) and MultiBit test (MBT) Apps. The primary aim was to determine participants' views about the acceptability of using the index tests. In addition, we explored adherence to weekly HM, and examined perspectives of family members and healthcare professionals providing support to participants as part of HM, including training patients for the study.

2. Methods

Qualitative methods were used to explore individual responses, views and experiences around HM acceptability, as well as to examine variations in contexts. Semi-structured interviews were conducted face-to-face and via telephone. The interview schedule was based on theories of technology acceptance[5]. The study followed the consolidated criteria for reporting qualitative research (COREQ) criteria[6]. Ethical approval was acquired from the National Research Ethics Service (IRAS ref: 232,253 REC ref: 17/NI/0235). Apps were pre-installed on an iPod touch device given to participants who were asked to complete weekly HM for a minimum of 12 months. Maximum variation sampling was used to ensure a range of perspectives were captured relating to age, gender, laterality of nAMD, and time since first treatment. Usage data was assessed to classify participants based on adherence to HM as: 'Regular' (completed weekly HM without two or more gaps in testing of greater than three weeks), or 'Irregular' testers (stopped and started testing on more than two occasions, or stopped testing completely). Interviews were audio-recorded and transcribed. A directed content analysis approach based on deductive and inductive coding was used. NVivo version 12 was used to manage data and facilitate the analysis process, which in summary included the following stages: i. Independent transcription, ii. Data familiarization, iii. Independent coding, iv. Development of an analytical framework, v. Indexing, vi. Charting and vii. Interpreting data.

Table 1. Sociodemographic characteristics

		Qualitative Sample (n = 78 *)		Remaining MONARCH Study Participants (n = 221)	
		n	%	n	%
Baseline characteristics					
Sex	Male	30	38.5	93	42.1
	Female	48	61.5	128	57.9
Age	Mean (SD) years	74.3 (6.8)	-	75.1 (6.6)	-
Visual acuity **	Mean (SD) LogMAR	0.2 (0.2)	-	0.2 (0.2)	-
Smoking history	Current smoker	7	9.1	23	10.4
	Ex-smoker (>1 month)	44	57.1	94	42.5
	Never smoked	26	33.8	104	47.1
Exposure to technology					
	Television	75	97.4	220	100.0
	Simple mobile phone	24	31.2	106	48.2
	Smartphone	53	68.8	145	65.9
	Tablet	55	71.4	142	64.5
	Laptop/Home Computer	53	68.8	132	60.0
	Internet at Home	68	88.3	185	84.1
	E-mail	62	80.5	152	69.1
	Social Media	30	39.0	68	30.9
	TV streaming/On-demand services	36	46.8	110	50.0

* Calculations are based on n = 77 as overall qualitative sample includes n = 1 participant who declined to take part in home monitoring but consented to take part in the qualitative part of the study. ** For patients with two involved eyes, better seeing eye is used.

3. Results

26% (78/297 of MONARCH participants) were interviewed. This included participants categorized as "regular" (n = 63) or "irregular" testers (n = 14) and "non-testers" who declined to take part in HM (n = 1). Characteristics of patient participants (n = 78) were comparable to those not taking part in the qualitative study (Table 1). In addition to the 78 patients, 11 informal 'carers', and 9 healthcare professionals were interviewed. A total of 98 interviews were completed (patients, carers and health professionals). Views about HM acceptability appeared to be represented by five overarching themes (and nine associated sub-themes): 1. The role of HM; 2. Suitability of procedures and instruments; 3. Experience of HM, and 4. Feasibility of HM in usual practice; 5. Impediments to home monitoring. Illustrative quotes are provided in Table 2.

Table 2. Perspectives of patients on acceptability of home monitoring

Perspectives of Patients	Theme/Sub-Theme	Supporting Quote(s) from Patients
- HM viewed as providing 'ownership' or 'personal control' - HM could reduce the frequency of clinic visits - Clear pathways to routine clinic appointments are needed if there are changes in visual acuity	Theme 1. The role of home monitoring Sub-theme 1: Understanding purpose Sub-theme 2: Perceived impact on eye care	*'. . . it is to put you in charge. I could judge if I needed help, if I saw deterioration in my vision when I did the test, or if I noticed a change by myself'.* (Female, Regular HM, 62 years, #53) *'I would feel, yes, I'm doing the tests and that's okay. At the minute, I'm only going (to the clinic) four times a year, so even two or three times would be okay. I'd be happy enough now [To home monitor], you know? . . . Providing nothing happens'.* (Female, Regular HM, 78 years, #37) *'. . . I don't think it would always work because it's near impossible to get an appointment, you know? I mean, I've done that. I've seen a change in shape, not when I was in this study but before. I asked for an appointment but didn't get it, so is the purpose is to try and put people more in charge of saying what they can see, saying if they need help or not?'* (Male, Regular HM, 82 years, #24)
- Overcoming unfamiliarity with technology regarded as 'something needing to be done' - Unfamiliarity with technology might result in hesitation about engaging in HM	Theme 2. Suitability of procedures and instruments	*'. . . technology is a funny thing to lots of people my age, some have embraced it, now of course it's a necessary evil, so I'm on catch up'* (Male, Regular HM, 76 years, #08) *'. . . if this (the test device) was just given to me, I would be a bit lost but I'm always trying to keep an open mind with technology and do what I can, you know.'* (Male, Irregular HM, 79 years, #38) *'. . . I mean it's no problem because I'm not too bad. I've got an iPad and an iPod, but I can see lots of people couldn't do it. A lot of them don't even like using the computer do they?'* (Female, Regular HM, 81 years, #68) *'. . . Well, mostly it's the elderly people that have got it (AMD) and most of them are not okay with computers and things. I mean I'm not brilliant, but I can do it. As you get older you can't learn these things so easily'.* (Female, Regular HM, 79 years, #82)
- Refresher training could help overcome difficulties recalling information - mVT and paper-based KSJ tests were perceived as less engaging than the MBT - MBT Test feedback seen as helpful for keeping engaged with HM - Lower test scores, even when small, were interpreted as a concern about their eye health	Theme 3. Experience of home monitoring procedures Sub-theme 1: Training for home monitoring Sub-theme 2: Test preferences Sub-theme 3: Use of MBT feedback and data	*'. . . and so (the clinic staff) demonstrated it . . . I thought that actually looks easy, but a week later when I'm on my own, I just said "what did they say?'* (Female, Regular HM, 71 years, #49) *'. . . well, I found that test (MBT) . . . first of all it was very quick. You had to be so alert and I could be pressing away and it was doing nothing because it was too fast for me'.* (Female, Regular HM, 76 years, #17) *'. . . but the test with the flashing numbers (MBT), I actually liked that. I couldn't stand the other test (mVT) because you get four shapes and one of them is sort of out of sync. The first three are easy, then it gets more and more tricky. It gets to the stage where I just had me guess. I actually found that annoying because I didn't know how I was doing. The other one you get a percentage, which is good'.* (Male, Regular HM, 80 years, #46) *'. . . so you see benefits instantly because you've got a result, not only have I done an exam, I have a result instantly, the minute you finish and put your stuff away, the mental benefits are there.* (Male, Regular HM, 75 years, #87) *'. . . if I get less than 90(%) then I absolutely know that there's something wrong. I'm not happy with 92, it's always been 94 or 96, 98, or 100. So that did worry me, but I will do it again, just to check, and I've got an appointment on the second anyway'.* (Male, Irregular HM, 77 years, #50)

- Several methods used to help continue regular HM, including use of reminders or prompts - Using other forms of digital 'self-monitoring', including blood pressure measurements; made it easier to set up a HM routine - HM needs to be 'easy, and not a burden' to achieve sustainability and high adherence - Family members were a source of support	Theme 4. Feasibility of regular home monitoring in usual service delivery Sub-theme 1: Frequency of home monitoring and habit formation Sub-theme 2: Use of ongoing support	*' … and (my granddaughter) would get it set up for me and then when that test is finished, switch over on to the next but she doesn't have to stand over me, you know.'* (Male, Irregular HM, 79 years, #38) *' … I have used that (monitoring device for tracking COPD symptoms) for about 18 months, so this can also helped me know when I'm getting bad, because they were reading it and then they were ringing back and checking with me. That made me feel better, being in touch with people'.* (Female, Regular HM, 62 years, #53) *' … when I first went back to [eye hospital] they gave me the bag and then when I went to [hospital] they gave me a blood pressure monitor, so what I do is, I have to check my blood pressure regularly you see, so I stick this in with my machine because I'm doing them both weekly at the minute and it all works out well, I don't forget'.* (Female, Regular HM, 74 years, #34) *' … my son has got me using smart phones and what not. I am ok with an iPad and an iPhone, no problem. I can handle anything in medical terms, I am keeping tabs on my medications on a daily basis. I have a little app that reminds me every hour, every two hours, what I have to do for the day'* (Male, Regular HM, 70 years, #136) *'..You don't do for enjoyment you're doing it to see how it goes. I don't look at it as a pleasure that I can't wait to do, and think, oh I must go up and do my wobbly circles. I just think it's time I did those, I'll go up and do them now'.* (Female, Regular HM, 66 years, #62) *' … I had a lot of trouble at one point, but my husband said, "let me have it,' and he diddled about with the buttons, one of which was the light intensity so I had probably turned the light down without realising it. He helped a lot. He said 'you go through it and see what you get stuck on. He didn't just take over, he just said call me when you need me'.* (Female, Regular HM, 72 years, #58) *' … so I had to ring [the helpline], he was very nice and went through it all. My son lives down the road and is into computers and I said well, I could ask my son again, but it was all sorted before my son appeared'.* (Female, Regular HM, 76 years, #16)
- Some adaptions made HM challenging and 'awkward'. - Other health concerns or functional limitations made it harder to undertake HM - Caregiving responsibilities made it difficult to find time for regular HM	Theme 5. Impediments to home monitoring Sub-theme 1: Practical issues Sub-theme 2: Personal health and social factors	*' … it was difficult, I just couldn't get it dark enough. I racked my brain and thought I've got a big wool rug. I got under that and did my best but there's also the claustrophobia, it just got me annoyed in the end'.* (Female, Irregular HM, 77 years, #33) *'..and I have a tremor, when I'm holding it (the iPod), you don't know where the numbers are going to come from on the screen … so you're sort of anticipating you know? And this means you just don't catch it'.* (Female, Regular HM, 71 years, #71) *' … I have had problems with my health, my heart scare, lots of things all happening, a lot of times I think this leaves me feeling really really tired... I'm staring, not knowing if I even hit the buttons'.* (Male, Irregular HM, 74 years, #29) *' … it's because I have been caring for (a relative) and I don't even remember. It's not high on my list of priorities. I have been doing it, but it's when I get to it, not when it gets to me'.* (Female, Regular HM, 72 years, #83)

HM: Home monitoring; mVT: MyVisionTrack®; KSJ: keepSightJournal; MBT: MultiBit test.

4. Discussion

This qualitative study investigates views of patients, informal 'carers' and healthcare professionals about acceptability of home monitoring for nAMD reactivation. Home monitoring was acceptable to participants and key factors such as patient's understanding of HM, and how it could be integrated into usual care appeared to influence these views. According to relatively younger patients, older peers might find HM to be a challenge– a perception also reflected in views of healthcare professionals. However, the factors that appeared to have a greater impact on positive views about HM acceptability were participants' perceptions around the usefulness of HM for eye care, how easy it was to complete weekly HM, and their experience of undertaking HM. Inexperience with using technology did not seem to limit or affect HM, or a participant's intention to use it, and experience relating specifically to other forms of digital monitoring of health symptoms (e.g., blood pressure monitoring or medication reminder apps) may have been a facilitating factor. Establishing the 'habit' of HM and integrating it into a participant's routine seemed to be important in terms of ensuring regular use. Weekly HM was feasible though more frequent monitoring (e.g., daily testing) may be too burdensome and, therefore, less acceptable. In general, the HM tests were reported to be easy to undertake and non-burdensome. The time commitment required to undertake HM was also acceptable and, although technical difficulties were relatively infrequent, access to

ongoing support was regarded as essential to successful HM, and for overcoming any unfamiliarity with use of technology. Support included 'formal' training and assistance from healthcare professionals with technical aspects of HM, and 'informal' support primarily from partners and family members in the form of encouragement and facilitation of HM, and to help manage in situ any technical issues. It was recognised that there was potential for HM to reduce the frequency of clinic visits, particularly during non-active treatment phases. The use of test performance feedback was perceived by participants as a way to 'self-monitor' vision, even though 'feedback' was provided by only one of the tests (the MBT).

5. Conclusions

This qualitative study provides important insights into the perspectives of patients, 'informal' carers and healthcare professionals about the acceptability of HM for assessing reactivation in nAMD. Home monitoring was acceptable and non-burdensome but initial training and ongoing support are essential to successful implementation. These findings have important implications for the design and use of digital HM in the care of older people with nAMD as well as in other long-term health conditions.

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