Exploring possibilities for AMD monitoring at home

A qualitative study on AMD monitoring via app

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Exploring possibilities for AMD monitoring at home

- A qualitative study on AMD monitoring via app

Research Projects and Clinical Optimization

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Content

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Aim of the study

The aim of the study is to investigate patient experiences regarding the use of two apps to monitor disease progression in patients with AMD. It is the overall aim of the study to investigate, whether one or both apps can be implemented for home monitoring. The qualitative study can thus shed light on possible hindrances and motivations regarding the use of the apps and a later implementation from the patient perspective.

Two apps, Alleye and MaculaScan, were tested in this study. While both apps were tested at Zealand University Hospital in Denmark, only the Alleye app was tested at the University Hospital in Lübeck.

Treatment practices today

In this section, current treatment practices in both countries are delineated. Even though patients with wet AMD are treated with injections in both countries, the workflow around and the organization of the treatment is quite different, which leads to different experiences among the interviewed AMD patients.

Germany

Patients in Germany are generally treated every four weeks. A visit in the clinic includes a pre-consultation, a thorough consultation and, if needed, treatment through injections. These three steps are all accomplished during one visit.

Denmark

Patients in Denmark visit the clinic depending on their individual treatment needs. While some patients thus visit the clinic every six weeks, while they are in a treatment cycle, other patients only visit the clinic every few months for their regular check-up. When the development of their AMD is halted and considered to be stable, patients are asked to come to the clinic with longer intervals, i.e., 3-4 months. As in Germany, a visit to the clinic includes a pre-consultation, a thorough consultation and, if needed, treatment through injections. These three steps are all accomplished during one visit.

Methods and data analysis

Germany

Observations and qualitative interviews were conducted at the Department of Ophthalmology at Lübeck University Hospital.

Nine patients suffering from wet AMD tested the app in connection with their monthly treatment at the clinic. The test was observed by a qualitative researcher who afterwards

conducted a short interview with the patients and, if present, their relatives. The interviews lasted approximately between 15-35 minutes and were recorded with a voice recorder.

The recordings were partially transcribed and analyzed.

About the interviewees

The interviewed German patients were between 65-88 years old and had been suffering from AMD between 1,5 and 10 years, most of them 5-6 years. All the interviewed patients had lost some sight on both eyes but in general had one eye that was less affected by the disease at the time of the interview than the other was. All the interviewed patients had been treated in the clinic between one year and ten years. Some had been treated in other clinics before but had made the change as they felt that they were treated better at this clinic. All patients had initially gone to their local practicing ophthalmologist, as is common practice in Germany.

Four of the interviews were conducted with the participation of the patients' relatives, e.g., their spouse or daughter, while at least three of the other interviewees had a relative waiting for them in the waiting area or in the car outside the clinic. The relatives that were present during the interviews, participated actively and shared their experiences of and attitudes towards the illness and treatment, and thus contributed with relevant insights.

At least 5 of the interviewed patients owned a smartphone and all but one patient explained that they were not interested in that kind of technology. The patients owning a smartphone explained that their use of technology was very limited mainly due to lack of interest but also lack of ability due to their bad eyesight.

Denmark

Observations and qualitative interviews were conducted at the Department of Ophthalmology at Zealand University Hospital.

Nine patients suffering from wet AMD tested the app in connection with their treatment at the clinic. The test was observed by a qualitative researcher who afterwards conducted a short interview with the patients and, if present, their relatives. The interviews lasted approximately between 10-35 minutes and were recorded with a voice recorder.

The recordings were partially transcribed and analyzed.

About the interviewees

The interviewed patients were between 67 and 87 years old and had been suffering from AMD between 2 months to 7 years, most of them 1-2 years.

All the interviewed patients had lost some sight on both eyes but in general had one eye that was less affected by the disease at the time of the interview than the other was. All the interviewed patients had been treated in the clinic between a couple of months and seven years.

Four of the interviews were conducted with the participation of the patients' relatives, e.g., their spouse or son/daughter/grandchild. The relatives that were present during the interviews, participated actively and shared their experiences of and attitudes towards the illness and treatment, and thus contributed with relevant insights.

Several themes emerged from the interviews and observations in Germany and Denmark that will be delineated in this section. While some of the themes emerged through design of the interview guide, other themes such as "practical hindrances" and "patients' relatives" emerged mainly as the informants themselves put great emphasis on their importance.

Results (Germany)

Level of digital competences and access to equipment

The level of digital competences vary greatly among the interviewed patients. At least five of the interviewed patients owned a smartphone. When asked about their use of technologies such as smartphones and tablets, most explained that they were not interested in that kind of technology.

The patients owning a smartphone explained that their use of technology was very limited mainly due to lack of interest but also lack of ability due to their bad eyesight. These technologies were mainly used for phone calls and text messages and only few of the patients had installed other apps. One patient (P3) and her husband explain that they own smartphones but use them for daily practicalities such as messaging, the weather report or gas prices. "*We limit it (the use of smartphones ed.) to daily use and no games*".

The patients who do not own a smartphone have varying reasons for this. One patient (P5) explains: "Let me just say, that I am not a fan of these electronics, no". While other patients such as P2, a woman suffering from dementia, have mental or physical disabilities that make the use of smartphones difficult.

General worries

Most of the patients and to a high degree their relatives expressed some general worries in the interviews. These are worries about how to fit the treatment into the everyday life, the cost of the treatment and the foreseeable degradation of their eyesight. Patients worry, if parts of their treatment will continue when a research project ends or which consequences the end of the treatment will have for their eyes.

Several patients also worry about the cost of treatment and are very concerned whether the use of an app for home monitoring would be covered by their insurance. P1 says: "It would be great, if it (the app ed.) would be free.". He explains that some costs in connection with the treatment are acceptable, but that he is worried about a "cost explosion". This worry about high and possibly unforeseeable costs is touched upon in several of the interviews.

Several patients also have other conditions beside the AMD e.g., dementia or heart conditions that increase concerns.

Patients' relatives

The patients' relatives play a large role in the lives of the patients. Several relatives participated actively in the interviews and talked about their concerns and wishes for the future.

Relatives potentially play a role in connection to the patients' use of the app. One patient (P8) says that now he is 81 years old, and that is why the app is not so interesting for him.

He states that he already controls himself. But, if his son said he should use the app, he would do it.

Patients are often driven to the clinic by their relatives as their decreased vision no longer allows them to drive a car themselves. Several patients and their relatives complain about the long waiting time between consultations and treatment and entire days spent in the clinic. "*For us it is a day trip*" says the relative to P1. Just as many of the other patients and relatives, she and her husband bring food and coffee to the clinic as a preparation for the hours of waiting.

Many of the interviewed relatives are also ill or have a medical condition. As the clinic is not very flexible regarding appointments, relatives often have to change their own medical appointments. Several relatives thus express that they must look past their own needs and adapt their plans to fit the clinic, which leads to frustrations.

The importance of treatment and seeing the doctor

Patients and their relatives often mention that even though the treatment may sometimes be burdensome, they would do anything to preserve as much of their vision as possible. One patient says: "*I am so glad that I am not blind (…) I would do anything to keep it that way*".

Many talk about an experienced decrease of their quality of life, for instance not being able to read, work or even hunt. One patient describes how he realized that some of his dreams would never come true, due to his fast and sudden loss of vision. "It is what it is" he shrugs. Some patients explain that it took a while for them to realize that the aim of the treatment merely was to avoid further loss of vision and that there would be no improvement.

The relative of a patient – an older woman suffering from dementia (P2), is concerned whether the app would be able to detect a worsening of the AMD just by testing whether the patients can see a straight line. She says: „*It is not just about the app or just about if the dot is on a straight line. Through that, you don't know if liquid was formed or not. And that's what it's about*". Even though she expresses that she is positive towards the use of an app at home, she does not see that the app could replace physical consultations with a doctor.

Practical hindrances

The interviewed patients and relatives point to several practical hindrances, which they think could pose a challenge for the implementation of the app. These worries include e.g. whether there would be a proper introduction to home use or whether it would it be possible to get an appointment at the clinic if the vision deteriorates. One relative (to P2) worries "*just because the app says, that the eye has deteriorated, there is not an available appointment (at the clinic ed.).*" whether there is a relative at home that can assist the patient.

Another patient (P9) contemplates that he would be able to use the app, but is concerned about whether he would be able to find the app on the screen and open it. The

observations show, that this could be a hindrance for several of the patients. P9 also worries that if it would not be for the clinic he would not now about the app because "*who would tell me about it?*". And he points out, that it is difficult for AMD patients to find information on new technologies or opportunities due to the nature of their illness.

Aiming for a good result

Many patients comment that they are eager to score a good result, which is interesting as many patients do not receive feedback on their efforts.

One patient, who did not see how he did on the test, says afterwards "*you do become a bit ambitious*" and explains that he tries to score a good result.

Another patient is frustrated that the result consists of an average score at the end instead of immediate feedback along the way. "*This way, at the end of the game you have a number, and you don't know how this number was generated*". He would prefer to be able to see his mistakes immediately to be able to practice and improve his result.

While many patients are very concerned with their results, there are also patients who show little interest. One patient (P5) explains: "*If I would ask (about my results ed.), they would tell me, but I trust my doctor completely*".

How to interpret the results

This is one of the major points, as almost all patients comment on their lack of understanding. They would not know how to react on their results. "*You could say from five (…) so you know, ok, now I really have to go there (to the clinic red.) to get checked.*"

Patients do not know whether a given number is a good result or not. They notice if the doctor comments on their result and emphasize if their doctor made a positive remark. Some patients explain that their doctor mentioned a result, but they do not know how to interpret the numbers. A few patients ask to know their results but only those that have received a comment from the doctor are satisfied with their result.

One patient says that he does not trust that the app test itself is good enough as an eye test because it only gives an average value. One value every four weeks would not be enough to make him feel safe.

Data sharing

While some of the patients were aware that the use of an app for monitoring their condition at home would mean that data would need to be transferred electronically, none were really worried about data safety. One relative to a patient explains that she trusts that an app provided by the hospital will be safe to use and also other patients stress that the app should be approved by the clinic. This emphasizes the patients' trust in their doctors.

One relative points out that the app can also be used by the clinic in order to keep an eye on the patients, while they are at home. She comments to her husband: „*then they (the doctors at the hospital ed.) can check exactly how often you are using the app*".

One patient comments that there is no data in the app that could do any damage and that it (the app ed.) is "*just like telemedicine*".

App functionality and user friendliness

This point is mostly a collection of results from the observations paired with comments from the patients.

Most patients call the app a *"game"* or *"toy"* and when asked about their experience with the app, several patients say that it is *"childlike easy"* or *"easy as a game"*. One patient says, *"Yes, it is a nice game (...) I think my grandson would like it as well"*.

Most patients commented that they found it extremely easy to use. Contrarily, the observations show that several patients had difficulty with the use of the app. Several patients would thus accidentally stop the test and have to restart it, which was creating frustration for both the patients and the doctors.

Some patients also had problems pushing the arrow button correctly (from above). Instead, they would slide their finger across the arrow, so the dot did not move.

The patients were instructed to hold the tablet still and look straight at it while using the app, which many found difficult due to their AMD. Instead, they tried to look at the screen from several perspectives to check whether the dots were aligned. This is a very important observation and should be considered if the app is tested for use at home. As many patients comment that they try to score a good result it is possible that they will look at the dots from several perspectives at home, if they are not instructed in why it is important to do otherwise.

Results (Denmark)

Level of digital competences and access to equipment

The attitude toward using the app at home and the ability to use it in the test situation is primarily dependent on the digital competences of the patient and whether they have access to for example computer, tablet, or smartphone at home.

The competences vary from advanced to none. In one end of the scale, we find (P2) a woman 74 who has computer and smartphone at home and uses several functions. She is an experienced IT user with developed competencies acquired through her former job. However even she says that she needs support from time to time from her son. She is positive towards home use as she sees benefits in saving transport time. She supposes that she would not need support from the department for home use. Actually, she does need support in the test situation.

At the other end of the scale is a man 85 years (P5). He has no smartphone, tablet, or PC at home. Letters from the authorities are sent on paper to him and his wife. He has no IT skills and has never learned to use a computer. He does not understand the purpose of the test.

In between these extremes, the rest of the patients are situated. Several, but not all, have tablets, smartphones or a computer at home, and they use these devices primarily for communication. Some of the patients express that they have the competences needed for home use, but the observations show that they still need guidance during the test as their illnesses and weakness prevent them from using the apps properly.

The lack of digital competences makes the patients nervous when it comes to home use of the apps. A woman 76 years (P1) for instance says that she does not know if there could be challenges in home monitoring for her. But when the interviewer asks what she would think about the sight being tested at home via apps and the results being sent to the department, she is dismissive: "*Now we are in on something to be sent and it would probably be difficult*". However, she cannot explain what it is that is difficult: *"I do not know. It's like just shutting it down if it's something I just cannot or have not tried before…"*

Even P7 a woman 76 years who seems to have good digital competencies says about technology: *"I'm just so scared to ruin something and lose some of what I have lying around*".

General worries

The Danish patients do not to the same degree as the German explicitly articulate worries for losing more of their vision. However, worries can be traced in the observed conversations, as when the doctor talks about the high price of medication and both the patient and her son agree that it is worth it to increase the chance of being able to maintain vision.

Nevertheless, several patients express a resignation or an adaptation to their loss of functionality: They have gotten used to the poor eyesight. For instance, a woman 79 years

(P3), tells that she does not feel restricted in her everyday life, although it can be more difficult to read newspapers and magazines: "*No, I can kind of do the same thing that I have been able to all the time. The only thing is, when I read in the newspaper or in magazines, it may well turn out that a bit of the word may disappear, but it is not with the left eye. There I can read well.*"

Some patients even deny that they have any trouble seeing or that the AMD is worsening. A patient (P6 man 82) says that he does not notice his AMD at all (he often repeats this during the conversation): *"I have not noticed it at all. I think I have seen well. Also, when I have driven a car."* It becomes clear during the interview, that his worries center around losing his driving license, more than about losing his sight.

The resignation can be understood in connection to the pronounced signs of ageing among the patients. Several have other serious conditions besides the AMD e.g., dementia or heart conditions, that increase concerns. Some of the patients have recently been submitted to the hospital for other conditions (blood clot, hip fracture) and seem very fragile in the test situation.

Patients' relatives

The majority of the interviewed come to the clinic together with a relative, either wife, son, or daughter. As in the German interviews, the relatives participate actively in the conversations with interviewer and with the doctor. It seems as if the relative often has a more realistic view on the patients´ abilities to use the app, than the patient herself: A woman 79 years (P3), who has shown difficulties in the test situation, hesitates a lot when she is directly asked if it was easy to figure out what she was going to do in the app with the grid lines. Her son replies: *"Mother is not digital at all. She does not have a computer or anything at home, so she is not used to using such a thing at all."*

The woman answers no to the question of whether she has a smartphone. The son corrects her, though, and says that she actually has; she explains that she only uses it to call and to send text messages: "*I cannot find out.. and I do not need anything else, I think…"*

The patients express clearly that they would have had trouble in attending the regular controls in the clinic without the relative, as they would forget them or have difficulties with the transport from home. A woman 76 years (P1) says:" *Usually I have my daughter with me. One of them – I have three, who joins me here at the hospital (…) They remember. They are my memory."*

If the patient has a relative, who is more competent in using digital equipment, he or she plays an important role when it comes to the question of using the app at home. Several of the interviewed are not confident with the technology but tell that a family member can help them finding out. In one case the relative who follows the patient to the clinic seems as resignated towards using technology as the patient: A man 85 years (P4) does not have a smartphone or tablet at home: "We cannot" (about the use of the app at home). They receive all mail by letter and not digitally. They get help from their grandson. They are driven by the grandson or take flextrafik if nothing else can be done. They can still drive a car, but do not dare to drive in the city.

The wife (83 years) describes the experience of not knowing and being able to use a computer: "*I feel that we have arrived at the post office too late. Young people today they learn it all from A to Z.*"

The importance of treatment and seeing the doctor

Obviously, treatment is vital for the patients. For the Danish interviewees, the experience of being watched over and controlled by the doctor through physical meetings seems crucial. Only one woman (74 years/P2), who has comprehensive technological competences gained through her work life, are positive towards the idea of monitoring herself at home. The rest of the patients all prefer seeing the doctor face to face, even if it means long time in transport.

To the question of whether she would use the app at home a woman 78 years (P9) gives a typical answer: "*No, I think it would be nice to get to the doctor*". When the interviewer asks why, she says: *"Security. Because I think it is quite important that you can see well and move around. The doctor can see if there have been changes and it provides security."*

The need for safety and trust is as well important for the relatives. A woman 67 years (P8) answers as well denying to the question of monitoring herself. Her daughter immediately says she would not feel comfortable with the app replacing any of the controls.

The man (85 years/P4) says he would not feel comfortable using the apps alone without the help of the doctor immediately: "*No, I would almost expect Anders to be there and press there*".

P6 man 82 years is asked, what he would think of testing his vision at home and sending the results to the department: "*No, I would rather come to him. I would rather do that. I want to be surer of that. So, if I do not do well enough with tablet there.* " And it is especially due to his fear of having to do something wrong: " *If I do not do it right ... then... and here it is done right. I am not sure, but I would rather do it so that it will be perfect* ."

Coming to the controls and having the possibility to talk to the doctor satisfies what can be interpreted as a huge need for care. The doctor stands as an appreciated authority deciding what is right and wrong, and he is given a surprisingly central position in relation to the patients' wellbeing.

But in contrast to the German patients the Danish ones do not explicitly utter grievance in connection to their eye disease.

Practical hindrances

The practical hinderances are connected to the lack of user friendliness, which become obvious in the test situation. Most patients have troubles in seeing the dots, pressing the buttons, and understanding the instructions.

As in Germany, patients mention that they are too old to learn how to use new technologies. It does not interest them, or they seem simply too tired and vulnerable to be able to acquire new competencies.

A woman 87 years (P5) has problems in understanding and answering the questions but mentions that she has just been to the hospital since she had broken her hip. Her relative says that it has gone downhill quite a lot in the last six months. She has fallen twice and has been hospitalized twice, which has narrowed her abilities down a lot. It would probably be too challenging for her to use the app at home (she thinks herself). The interview is interrupted as the patient has difficulty in following the conversation.

When the interviewer asks what P1 would think about the fact that the vision was tested at home via apps, and that the results were sent to the department, she is dismissive: "Now we are talking about something to be sent and it would probably be difficult". However, she cannot explain what it is that is difficult: *"I do not know. It's like just shutting it down if it's something I just can not or have not tried before… "*. She would be very sad to have it at home.

Aiming for a good result

Also, some of the Danish patients comment that they are keen on scoring a good result. P2 the woman 74-years old who has advanced digital competencies says that she would have liked to see the results of the test. It would be motivating for her to see her score: *"Sometimes, if you go into such tests - if you go into some word tests or years or something like that, then it is very nice to know how many you have right."*

P8 a woman 67 years queries into her result. Her daughter remember that her result was 33 and they talk about whether it is a bad or a good result. The patients herself says she would find it exciting to know.

The understanding of the apps and the results

None of the Danish patients seem sure how to comprehend the results from the test. Some are interested in knowing what the test shows and ask the doctor for translation. A woman 78 years (P9) who has fundamental IT-competencies and uses the apps without problems says *"It's just my curiosity and nothing else. I cannot change anything anyway. But I would like to be part of what is going on that concerns myself."*

Other patients seem to have such a poor level of functioning that they do not have the ability or energy to be curious about their results. The observations show that some of them even do not understand the purpose of the apps. P8 woman 67 years for instance says about the use of the two apps: "*I'm sure I did not hit right" (laughs a little), but I think it is a very good way to practice your eyes with it with the dots.*" She has the impression that you could train your eyes through the app -which you cannot.

The man 85 years (P4) declares that he would like to use the apps if it can help anyone. It does not seem that he really understands the purpose of the apps.

Data sharing

None of the patients expresses hesitations toward data sharing – except for the practical hindrances.

App functionality and user friendliness

As in Germany, most patients commented that they found the apps easy to use. But the observations show that several patients in fact had difficulties when using them.

The test situations show several obstacles when it comes to using the apps: difficulties in finding the right buttons to press, shaking fingers, and challenges in understanding the meaning of using the app. The patients to a larger or lesser degree needs introduction and guidance from the doctor during the test.

P5 says she has not seen an Amsler chart before until the doctor showed it to her. She thinks she has once seen a curved flagpole or the like. When she has to draw on the Amsler card, she says "well, it's everywhere". The doctor presses the buttons for her at the black app. She says: "I can't keep up" and usually has to show the flashing lines again.

She shakes her hands a lot, which makes it difficult for her to press the right buttons. She has to give up the test of the app with the dots as she cannot see all the dots, shakes her hands too much and coughs a lot.

A woman 79, (P3) has a hard time with the black app, and it is the doctor who ends up pressing the buttons for her. With the dot app, she understands the system, but has difficulty pressing the middle round button. "*Yes, because I could not really see them (the arrows) down there*".

P9 says she thinks the apps were fine to use, but the app with the squares she thought was a bit difficult. She could not focus on the dot in the middle and at the same time on the squares when they were in the outer edge.

Difficulties like these may as well hinder implementation at home.

Lack of understanding of the purpose of the apps may as well lead to hinderances. For instance, P7 is able to use both apps. However, it seems as if she does not realize the intention of using them. When she is asked what she thinks about using the apps at home, she starts talking about the importance of having an ophthalmologist nearby, as otherwise, she must arrange transportation. The interviewer asks if she would feel safe with the controls being replaced by the app, and she reply, if they can do that? Whether she would feel comfortable with home use would also depend on how far it is to her eye doctor, she answers.

Conclusion

The interviews and observations show that the level of digital competences and access to equipment is very diverse among the older patients.

Worries about losing one's sight are expressed clearly among the German patients, whereas the Danish patients seem to have adapted to their level of functioning or even have resigned. The fact that many of them suffer from several serious diseases can offer an explanation to the resignment.

Patients' relatives play a central role in both countries. They support the patients in understanding information during the consultations and in remembering questions to the doctor. They fill out many functions in the life of the patients, as caregivers, as providing technical support, arranging transportation, etc.

Treatment is of course crucial to all patients. Especially for the Danish ones seeing the doctor face to face appears as necessary for their feeling of security. Several are not in a position where they have the energy or abilities to take more responsibility for their own illness.

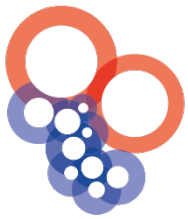
Practical hindrances for using the apps at home are closely intertwined with the question of app functionality and user friendliness. The relatively low degree of digital competencies among the patients is a serious hindrance for their use of the apps. Also, the co-morbidity prevents patients from using them. Several do not understand how and why they should use the apps at home, and they cannot interpret the results. Many of the interviewed patients are deeply dependent on their relatives. Both when it comes to physical consultations in the clinic, as well as the use of an app. This should be considered in an implementation process.

Patients seem to be aiming for a good result, and they make an effort to minimize their difficulties with the use. This *potentially* can blur worsening in their sight if they use the apps at home and thereby create a risk of health professionals overlooking realities.

Methodologically this finding suggests that topics like the one researched here, cannot be investigated solely through interviews, as this group of older patients strive to appear as having less troubles with technology than they in fact have.

No patients expressed hesitations in relation to data sharing. This could however be due to the lack of understanding of the intention with the apps.

It can be concluded that the apps in their present form are not suitable for replacing regularly visits at the eye clinic with home measuring for this group of older patients. It is a question if home use could be successful even with improved user friendliness as the psychological need for security through visiting the doctor seem strong.



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