

Research Article

Is Social Media the Answer to the Support Desired by People with Rheumatoid Arthritis? A Qualitative Exploration

Serena Peirce¹, Inam Haq², Simon Otter^{1*}

¹School of Health Sciences, University of Brighton, Robert Dodd Building, UK

²School of Medicine, Faculty Medicine and Health, Edward Ford Building, University of Sydney, Australia

***Corresponding author:** Simon Otter, School of Health Sciences, University of Brighton, Robert Dodd Building, 49 Darley Road, Eastbourne, BN20 7UR, UK. Tel: +44-12736445434; Fax: +44-1273643651; Email: s.otter@brighton.ac.uk

Citation: Peirce S, Haq I, Otter S, (2018) Is Social Media The Answer To The Support Desired By People With Rheumatoid Arthritis? A Qualitative Exploration. Advanc Rheumatol Artho: ARO-122. DOI: 10.29021/ARO -122. 100022.

Received date: 27 September, 2018; **Accepted date:** 2 November, 2018; **Published date:** 9 November, 2018

Abstract

There is limited literature surrounding social media in relation to inflammatory arthritis. We aimed to explore the role of social media and the use of software applications (apps) by people with Rheumatoid Arthritis (RA).

Semi-structured interviews with 14 people with RA explored their current use of social media and how this informed disease management. Thematic analysis was undertaken using NVivo using an IPA approach.

Four key themes were identified (1. arthritis and life, 2. finding support, 3. disease management, 4. using social media), with an overriding theme of disease ownership. The immediacy of support and information provided by social media was advantageous. The desire for more patient-centered social media resources to provide support was noted as was a specific app tailored to the individual.

Participants found social media provided useful support. The creation of a patient-centered app to aid disease management and thus disease ownership was seen as beneficial.

Introduction

Rheumatoid Arthritis (RA) typically affects small joints of the hands and feet in a symmetrical pattern [1], causing synovial inflammation and joint destruction, muscle atrophy and loss of function [1,2]. The pain and joint deformity are often associated with disability, depressive symptoms, a negative impact on social relationships and poorer health related quality of life [3-5]. Key to more successful outcomes in chronic disease are effective self-management strategies [6], particularly as long-term conditions such as RA have been associated with poor treatment adherence and less positive outcomes [7].

Social media encompasses services including blogs, wikis, virtual worlds and social networking sites that utilise platforms to integrate participation, communication, user-centeredness, collaboration and openness [8]. Social media usage continues to grow worldwide with a projection of 2.77 billion users by 2019, up from 2.46 billion in 2017 [9]. In the UK, almost three quarters of adults use mobile devices for internet access, more than double

the number reported in 2011 [10]. Social media is now part of daily life for many, routinely used for entertainment, education, financial management, and increasingly for health information and support [11].

Those with chronic disease are more likely to use social media to access health literature and aid self-management [12]. Users create and link networks of people with shared interests/experiences in a user-centric and collaborative manner, which could play an important role in patient-centred care [9,11,13]. Virtual worlds and online discussions have facilitated the creation of a collective forum of knowledge about chronic medical conditions that was seldom previously accessed [12]. Using social media to access information can empower and support those with RA and provide an alternative resource that will reduce the burden of treatment and ease social pressures [12]. In chronic disease management where lifestyle behaviours can have an impact upon people's wellbeing, this approach is valuable [11,14]. Social media may not only ease the burden of self-management in chronic disease, but also offer opportunities to meet patients' needs that

are not met in traditional face-to-face clinical encounters [15]. Potentially, health professionals could share accurate, real-time health information while maintaining professional boundaries and patients' privacy rights [11, 14-16], the latter being a particular concern for patients and professionals alike [17].

Software applications (apps) are computer programmes designed to run on mobile devices (smartphones, tablets or smartwatches). The use of apps on mobile phones has increased considerably, and varies with the user's context, location and the time of day [18,19]. In healthcare, many apps can assist practitioners with day-to-day tasks (time management, e-records, consultations, information gathering, patient monitoring, and so on) [19], and in some chronic diseases, such as diabetes, apps currently exist to aid self-management [18,19]. A recent systematic review concluded that mobile devices with enabled apps could perform important roles in patient education, self-management, and remote monitoring [20].

In RA, disease activity calculators [20] and forums for symptom reporting [21] do exist, but there is limited evidence of social media usage, or of professionals recognising the potential role of apps in the self-management of inflammatory arthritis.

This study aimed firstly to explore the use of social media and of apps by people with rheumatoid arthritis. Secondly to determine whether current technologies are used to manage health and wellbeing, as relatively little is known about patients' perspectives and motives for social media usage in this chronic condition.

Materials and Methods

Study Design

A qualitative exploration was implemented using semi-structured, face-to-face and telephone interviews with people with RA. A modified Interpretative Phenomenological Approach (IPA) was adopted, [22,23] allowing for a rigorous exploration of idiographic subjective experiences as applied to practice [24-27].

Interview Schedule Development

The draft interview schedule was developed following an

Arthritis Research UK (ARUK) Stakeholders' Education Day in which the researcher [SP] facilitated a group discussion entitled 'Delivery of patient information in the 21st Century: opportunities and challenges'. In that discussion, expert patients, consultant rheumatologists, podiatrists, specialist nurses, physiotherapists and members of the ARUK directorate covered topics including social media, education and patient experience. Field notes and a transcribed recording of the discussion were utilised to inform the interview schedule. In line with methods adopted by Turner and Coyle [28], findings from our review of the literature surrounding social media and RA were also employed to inform the interview schedule. The key areas for exploration included: perception and experience of rheumatoid arthritis, use of social media, and the role of software applications in disease self-management.

A draft schedule was distributed amongst the research team and amended prior to the pilot study, then piloted in two telephone interviews to ensure face and content validity. Following these pilot interviews, it was further refined by including additional questions and prompts. These modifications were made in an attempt to capture a complete illustration of the disease and its impact on the lives of the respondents, from diagnosis to the present day. The initial interview schedule formed the basis for conversation, with minimal additional prompts [22]. It was used to facilitate the gathering of verbatim participant accounts; a central premise of IPA [23]. Open-ended questions were posed to allow for the introduction of new topics [29] and to ensure that participants' observations on the subject were not restricted.

Subjects and setting

The University of Brighton granted ethical approval. A purposive sample of people with RA, aged over 18, with a positive diagnosis of RA and an existing interest in, or knowledge of, social media were invited to participate via email, tweet and Facebook post from the National Rheumatoid Arthritis Society (NRAS) and Arthritis Research UK (ARUK). Those interested opted to participate and information about the study were emailed in order to gain informed consent. Interviews (either face-to-face or telephone) used the same interview schedule by one researcher (SP), throughout (Table 1).

Interview Schedule

Questions	Prompts
1) Can you tell me about your arthritis?	How long have you had arthritis?
	What medication do you take?
	How has your arthritis affected you?
	Are you working at the moment?
	Does it affect your hands?
2) Can you remember the diagnosis process?	Did you have to take results to many different doctors?
3) Do you currently use social media resources provided by Charities or support groups for people with arthritis?	Do you use social networking sites e.g. Facebook or Twitter?
	Who do you follow on Twitter and why?
	Have you ever downloaded any 'apps' from charities or support groups e.g. NASS
4) Can you tell me about how you use social media resources?	How often do you use it? Do you find it helpful?
	Do you find your choice of resources limited?
	Could you elaborate on these limitations?
5) What sort of information, advice and support do you feel you currently receive from these resources?	What information or advice or support would you like to receive from these resources?
6) What sort of phone do you have?	
7) Can you tell me what 'apps' you have on your phone/iPad/tablet at the moment?	How often do you use them?
	What made you download them?
8) Do you use social media in other ways?	How do you use social media?
	Do you use health & fitness apps, community support groups, networking sites to manage aspects of your life etc?
9) Can you think how social media might be used to enhance the well-being of people with arthritis?	Do you feel arthritis has affected your quality of life?
	Is managing your own health important to you?
	Do you use the methotrexate monitoring book for results?
	Where do you get your blood tests done?
	Is there a good communication with health professionals?
	Do you remember your hospital appointments?
10) If a smartphone app were to be developed to store, record, create and link arthritis information and care over a period of time would you find this useful?	Have you ever used the Nike app? (show the app)
	Is recording health test results etc important to you?
	What information collected would you find useful in discussion with your health professional e.g. pain?
	Does this change depending on your activities?
11) If you can think back to the earlier question about your diagnosis process, how do you think a smartphone app would have been beneficial during those stages? And How would it be useful now?	E.g. Photo feature or blood test reminder?

(Table 1) Appendix-1: Interview Schedule.

Data Analysis

Each interview was audio taped and transcribed verbatim independently, pseudonyms were applied to maintain anonymity [30]. Data were firstly analysed using *NIvivo* (v11) and indexed according to nodes and clusters [31]. Secondly, close reading and re-reading of the transcripts ensured familiarity with the text [22,32]. Preliminary themes were identified, followed by groups of themes and clusters. Themes were selected based on their prevalence within the transcripts. Similarities, differences, articulacy and eloquence of the participants in their explanations were noted in an attempt to reduce bias when selecting themes [33,34]. Collating the data from both analyses (*NIvivo* and close reading) resulted in the final themes [33]. A final re-reading of the original transcripts was made to ensure that interpretations were grounded in the participants’ narratives [35]. Once the themes were formulated, these were checked by one of the research team [SO] to ensure the credibility and trustworthiness of the data [36,37]. The use of verbatim quotes is central to IPA [28] and exemplars have been included (using pseudonyms) to articulate each theme [29].

Results

Of the 25 people recruited, 14 participated (8 telephone interviews, 6 face-to-face interviews). All participants were female (mean age 38.5 (SD 9.9)), and mean disease duration was 12.2 (SD 15.9) years. The demographic data is detailed in (Table 2).

Participant Psuedonym	Age (Years) (mean 38.5, SD 9.9)	Duration of RA (Years) (Mean 12.2, SD 15.9)	Occupation
Rachel	29	2	Not disclosed
Rebecca	46	44	Human Resources
Ruth	33	13	Graphic Designer
Rosemary	41	2	Occupational Therapy Assistant
Renee	34	29	Unemployed
Rosetta	55	47	University staff
Rosalie	41	2	Unemployed
Rita	26	2	Nursery Nurse
Ruby	40	3	Accounts
Rowena	36	7	Research Staff
Riley	28	0.4	Activity Co-ordinator
Reese	26	7	Human Resources
Rosanna	51	8	Postal office
Roxanne	53	4	Communications officer

Table 2: Demographic details of participants.

In total, four major themes were identified, which are described in detail below and illustrated with verbatim interview extracts.

Arthritis and Life

The core theme, ‘Arthritis and life’, characterised powerful, expressive speech that demonstrated how participants’ lives were now unrecognisable.

“I’m scared that I might die young because of my illness, I can’t lead a happy lifestyle, I don’t want this [Rheumatoid Arthritis] controlling my life. I control it, it don’t control me.” (Rita, 26).

Prior to diagnosis, most participants were employed, with active social and family lives. Their RA caused tremendous disruption that required physical, psychological, social and emotional adaptations, which impacted significantly on everyday life.

“I’ve become more introverted and that’s simply because I’ve felt so unhappy.” (Rosalie, 41)

“I feel like it [RA] has ruined my life” (Renee, 34)

“It [RA] has destroyed me, I am just so angry with it, because I am a young girl.” (Rita, 26) Importantly, it was reported that everyday routines had to be altered to cope with the challenges of incorporating medication regimes and coping with side-effects. Additionally, considerable effort was required to adapt working lives to fit in a variety of routine appointments:

“It’s like having another career just to keep the disease on maintenance level it’s a lot of upkeep that people don’t realise or appreciate. I’m forever having to manage my work life around it.” (Ruth, 33).

“It’s just frustrating because I was such a busy person and I was doing so much voluntary and working for other people and now it’s role reversal people want to help me” (Riley, 28).

The profound disruption to the lives of these women highlighted their need to identify new methods of support. They reported that social media often filled this role as the use of Facebook or Twitter enabled contact with people with similar experiences in a much wider geographical area.

“Online I can talk to people all over the world and get their experiences and feedback and also get their support. Even if I just tweet ‘I’m having a rubbish day, something hurts’, it’s nice to get messages back from other people, ‘I know how you feel’ and I certainly wouldn’t have that if I didn’t have Twitter and Facebook.” (Rachel, 29)

“I use Facebook just to keep in contact with people round the world. I have recently joined the National Rheumatoid Association Forum, which has been helpful, it’s lovely having their advice and

input on what I should be doing to look after myself.” (Riley, 28).

Finding Support

The concept of ‘finding support’ was important to all, with a strong consensus about the lack of available literature, when they needed it. This was particularly so for family and friends who needed to understand a disease that is not always clearly visible. Without information the onus was on participants themselves to educate friends and family. Participants expressed a need for further information about their disease, treatments and management so that they could take ownership and maintain a significant level of independence.

“There isn’t enough information around, especially for people that don’t have arthritis.” (Reese, 26), “I found it incredibly hard to find information that my husband or close friends can read” (Rosemary, 41).

It was frequently necessary, particularly for younger subjects, to talk about the effects of their often invisible disease, in order to counter the feeling of being a burden “It’s obviously been quite difficult for my husband to get to grips with, ”why can’t you manage things?” Because it’s all quite invisible at times” (Rosemary, 41).

Respondents turned to various modes of communication (including friends, online support groups and social media) to find the required information.

“I’ve enjoyed having social media, having interaction with other people who have the same disease as me, probably more so because of my age” (Rachel, 29).

“Especially if I’m having a bad day, a really bad day, I tend to go on there [Twitter] and catch up with a few people, and then I think, ‘oh actually it’s not so bad” (Rosemary, 44).

“I’ve been blogging about my condition, I find that really therapeutic” (Renee, 34).

The use of social media for support was described and presented a paradox between anonymity and familiarity. Some social media platforms permitted users to maintain a level of anonymity whilst connecting with familiar users and topics as a support mechanism. For example, ‘PatientsLikeMe’ permits users to maintain their anonymity, whereas with ‘Facebook’ and ‘Twitter’, identity is more visible. Apps were frequently mentioned as mechanisms for connecting with a range of social media. Online communication itself proved to be a useful way to avoid isolation. Indeed, respondents who had used social media in this way did not necessarily realise that they needed support until it was there.

“I needed more support and I wanted people to talk to, so I found that’s how I found NRAS really” (Rebecca, 46).

“I wanted to be connected because I’ve never really been, I’ve never met anyone in my situation before” (Ruth, 33).

Some respondents reported turning to social media specifically for information on support, but in doing so found that social media was itself a support tool.

“I often found it [online communication] a good way of supporting myself when I was feeling a bit lonely and in a lot of pain” (Rebecca, 46).

“I definitely get support and information back from it [Social Media]” (Ruth, 33).

Disease Management

The issues around initial diagnosis, on-going medication reviews and disease monitoring were identified as areas that played a major role in participants’ lives. For most, their RA diagnosis was life-changing and many reported taking several types of medication in numerous combinations. Consequently, they had devised meticulous recording systems for their medication regime.

“I do it [Record Medication Data] in 17 different places, and like reminders on the calendar to put my prescription in or reminders on somewhere else to have the appointment or whatever. If it was all in one place it wouldn’t take very long for me to get used to doing it all in one place” (Rachel, 29).

In addition, participants reported remembering and noting side effects, and mentioned the importance of attending regular blood tests and review appointments. Taken together, this was both frustrating and time consuming. One respondent summed up the impact this had on psychosocial wellbeing and everyday existence.

“I want to be in control, desperate to be in control” (Rosetta, 55).

While routine blood tests, reviews and follow-up appointments interfered with the ‘normality’ that once existed, participants expressed a desire to take ownership of their disease and greater responsibility for disease management. This, they felt, would give them greater control of their everyday lives. Respondents were desperate to take control of their own disease. If they could not control its course, at least they could manage it by taking ownership. The provision of software which would give structure and help with organisation was seen to be a core method of improving control. The respondents positively described the benefits this could provide for them if it were made available via mobile device in the form of an app.

“One place [referring to an app] where I could go and it would tell me where my hospital visits and my blood appointments and all that sort of thing were without having to take all the paperwork” (Rosanna, 51).

“I wanted to be connected because I’ve never really been, I’ve never met anyone in my situation before” (Ruth, 33).

Some respondents reported turning to social media specifically for information on support, but in doing so found that social media was itself a support tool.

“I often found it [online communication] a good way of supporting myself when I was feeling a bit lonely and in a lot of pain” (Rebecca, 46).

“I definitely get support and information back from it [Social Media]” (Ruth, 33).

Disease Management

The issues around initial diagnosis, on-going medication reviews and disease monitoring were identified as areas that played a major role in participants’ lives. For most, their RA diagnosis was life-changing and many reported taking several types of medication in numerous combinations. Consequently, they had devised meticulous recording systems for their medication regime.

“I do it [Record Medication Data] in 17 different places, and like reminders on the calendar to put my prescription in or reminders on somewhere else to have the appointment or whatever. If it was all in one place it wouldn’t take very long for me to get used to doing it all in one place” (Rachel, 29).

In addition, participants reported remembering and noting side effects, and mentioned the importance of attending regular blood tests and review appointments. Taken together, this was both frustrating and time consuming. One respondent summed up the impact this had on psychosocial wellbeing and everyday existence.

“I want to be in control, desperate to be in control” (Rosetta, 55).

While routine blood tests, reviews and follow-up appointments interfered with the ‘normality’ that once existed, participants expressed a desire to take ownership of their disease and greater responsibility for disease management. This, they felt, would give them greater control of their everyday lives. Respondents were desperate to take control of their own disease. If they could not control its course, at least they could manage it by taking ownership. The provision of software which would give structure and help with organisation was seen to be a core method of improving control. The respondents positively described the benefits this could provide for them if it were made available via mobile device in the form of an app.

“One place [referring to an app] where I could go and it would tell me where my hospital visits and my blood appointments and all that sort of thing were without having to take all the paperwork” (Rosanna, 51).

“It would be really nice to have some kind of app to keep my blood results” (Ruth, 33).

“Having everything inside of one app social networks somewhere where you can log your medical monitoring, blood lab results, I think that would be really beneficial” (Renee, 34).

Recording their symptoms on a disease timeline, using cumbersome hard copy media such as diaries and calendars, or computer spread-sheets and online calendars (or a mixture of both) enabled the development of a sense of ownership and a coping mechanism for some, and more widely reflected respondents’ desire to take control of their disease. If this process could be digitised to work on mobile technologies such as tablets or smart phones, participants could identify clear benefits:

“If you’ve got an app you do things with it, but by the time you get to the consultant, if you’re waiting six months you know, you think oh there’s no point filling in three months ago, or you’ve forgotten about it. Whereas if you’ve got your phone you always have that with you and you could just click on it” (Roxanne, 53).

The Role of Social Media

Respondents reflected on their disease, its diagnosis and how they had used social media to aid them through this life-changing event, particularly where cessation of activities or sporting hobbies after diagnosis had negatively affected self-reported quality-of-life.

“I did feel quite isolated, I must admit, because obviously all my friends and most of my family were at work during the day and I started to get quite low and feel quite isolated. So I must admit my use of Facebook increased and that’s actually when I went onto Twitter. I tend to use Twitter more for having other people that have got things with a rheumatology interest or conditions, so that’s definitely much more on Twitter. Facebook tends to be my sort of family and friends” (Rosemary, 41).

The use of social media also enabled exploration of new hobbies. For example, one respondent reported that she had replaced her favourite sporting activities with non-active ones, making more use of social media: for example, online blogging and photograph sharing. Regular use of specific social media (blogs, Facebook, Twitter, YouTube and health-related internet sites) also provided increased disease knowledge and enhanced coping mechanisms, which provided support and helped participants to avoid isolation, thus facilitating disease ownership.

“I found when I first got diagnosed that I was whinging a lot on Facebook, because I was in so much pain” (Ruby, 41).

“Twitter that was the main reason I went on there because I knew there was somebody on there that knew how I felt and felt that I could talk to them as much as I’ve got good support from my

family and friends, I don't feel they completely understand" (Rosemary, 41).

"The majority of the time I use Facebook especially when you're a bit down it's nice to just have a rant, rather than take it out on my husband" (Roseanna, 51).

The immediacy of information and support provided by social media and the ability to follow others with rheumatic disease, gaining information, explaining the disease to others and feeling informed about novel therapies, were all identified as invaluable.

For some respondents, apps were helpful in their everyday lives, for example, easing activities such as ensuring a taxi is outside when it is difficult to stand/walk. Others were utilising apps to monitor their disease - for example photography apps to record their swollen joints to present to their health professionals at their next appointment. Respondents were eager to share ideas about how apps could be better employed to further develop monitoring, management and disease ownership.

"I think for me to have my own information stored would be amazing, I would love that, if say blood results could be pinged over to the hospital and they could say 'Ok this doesn't look good, you should come in', that can speed things up...information could be transmitted between me and the doctors, it would ease communication" (Ruth, 33).

"I think it [an app] would be a really big help a feature where you could log in all the medications you take...and if you need to take them at set times, you could have reminders so that you don't forget. You could have all your contact numbers on there for people, like your consultant's details, GP's details just in case you're out and about" (Reese, 26).

Some core features for any potential app (for example, storage of test results, medication data and disease information) seemed relevant to all.

"If it was all stored in an app, all my drugs and which I had and what I was allowed and how many of them I needed and I could automatically request a repeat prescription to be submitted" (Rachel, 29).

Participants emphasised that an app that facilitates coping and disease management may also permit a level of normality. Using an app to manage disease so that it would fit into everyday life by reducing the focus upon it, and thereby allowing a greater level of normality, was a popular concept.

Discussion

Social media has tremendous potential as a source of support for people with RA, and to the best of our knowledge, this is the first study to explore how they currently make use of

it. The detailed narratives revealed participants' personal in-depth thoughts, feelings, experiences and requirements relating to social media and uncover its use as a coping mechanism and means of taking disease ownership. This study suggests that, for people with RA, social media usage is already beneficial. The development of more specific software to aid their disease management would be valuable, particularly if this were available on mobile devices. Respondents were already using apps to manage other everyday tasks, such as online banking, and this behaviour could be replicated with patient-centred disease management in mind.

Across the four key themes there was an over-arching theme of disease ownership. Improvements in self-management [6,30] has been reported to be proportional to improved patient outcomes [38]. Our respondents reported social media was being used for support and self-management; to improve perceived self-efficacy, promote independence and to develop and maintain social relationships. In line with previous work [8,17,39], participants detailed the advantages of social media (availability and accessibility), which afford flexibility, control and ownership over when, where, if and how they interact [39]. Portable devices are highly valued by individuals, and are commonly used - especially by women [40-42]. These devices tend to be permanently switched on and remain with the owner throughout the day, offering the opportunity to make real-time interventions. Our respondents felt that linking their disease information to existing social media platforms would be helpful. While some sites purport to offer this facility [43], not all features desired by participants are available. While high quality information is provided by some websites [44,45]. Such information tends to be generic, whereas social media has the ability to offer real-time personal support from users.

Work by Azevedo, et al. [46] reported an inability to fully engage in self-management behaviours after diagnosis, due to either a lack of awareness of the importance of self-management, or a lack of knowledge about what to do. In evaluating the usefulness of a hypothetical smartphone app to support RA self-management [46], 86% of participants agreed it would be useful to develop a similar app and 94% believed it could facilitate a more active role in self-management. Our participants displayed a sound knowledge of positive self-management behaviours, but were overwhelmed by the existing online and print resources typically available at diagnosis.

Ensuring the credibility and reliability of information provided within apps, security and privacy issues, standardisation and potential conflicts of interest would all need to be considered if a specific app were to be developed [6,8,17]. The integration of apps with other aspects of patient care, including the use of electronic health records and patient portals, would be a pivotal step in advancing mobile health, but legitimate concerns about privacy would need particular attention.

Patrick, et al. [39] report that apps aimed at improving health tend to provide information, advice, instruction/prompts, support, and encouragement as well as interactive tools for individuals to monitor and record symptoms. In other health fields parallels exist in the concept surrounding self-management. The Diabetes UK tracker app [19] provides users with a quick and simple, effective method of managing their diabetes

The UK National Rheumatoid Arthritis Society have an app for tracking Disease activity scores [20] and a symptom tracking app exists in the US [21]. Interestingly, our participants listed characteristics for their own ideal hypothetical app (Table 3), which were above and beyond straightforward tracking of symptoms. ‘Treat-to-Target initiatives [47] and the need to fund expensive biologic medication, mean that there is a requirement to focus on disease activity scores and quantitative measures to push the patient through the treatment flowchart. This tends to lead to less focus on a holistic and individualised consideration of the nature of a persons’ arthritis. Many of the features in which our participants expressed an interest take advantage of diverse technologies that provide and maximise user-friendly visual graphics and speech animations to suit a variety of needs.

Store blood test results
Graphical presentation of blood test results
Appointment facility
Appointment organiser
Medication organiser including updates, delivery dates,
Medication reminder
Explanation of medications
Warning when dosage changes to ensure frequent blood testing occurs
Prescription generator
Diary to record relationships between food and flare-ups or activities and flare-ups
Record of side effects of medication
Pain diary - with faces and tick boxes
Timeline of health
Graphical presentation of previous 3-6 months of health outcome data
Communication of results between patient and hospital or GP
Social medial platform connection with peers
Virtual engagement with peers
Information for newly diagnosed patients

Terminology and abbreviations explained
Personalisation of app according to the individual’s disease
Information that could be used when on holiday in case flare-up occurs e.g. health record to show overseas health professionals
Information on local pharmacies that is updated depending on the area or country you are in e.g. similar to the display of petrol stations on a satnav
Health professional contact details e.g. rheumatologist, podiatrist etc.
Digital leaflets e.g. how to cope at work
Photography option to record new symptoms or changes in disease and linked to a date and time period

Table 3 – Characteristics a disease management app should ideally contain

Our findings were supported by Hootman, et al. [48] who suggested that, because of the hand pain/deformity experienced by some with RA, using newer touch-screen technology is a simpler method of navigating health resources. Despite the positivity surrounding health-related apps, there are important considerations associated with security, linguistic barriers and low levels of health e-literacy. Nevertheless, disease management apps have the potential to aid patients’ disease ownership and self-management and, if permitted, provide information for friends, family and clinicians.

The strengths of this work are a patient-centred and patient-derived exploration that offers a richer understanding of the daily struggles of those with RA and the opportunity technology offers to make improvements in patients’ lives. Equally, this work is subject to limitations. The interviewer was female, and the sample was all-female with an interest in health-related apps. While using a single gender population may raise questions about the generalisability of the work, RA predominantly affects the female population [49]. Gender is an important consideration in conducting interviews [50] and in this case it is possible this may have led to greater disclosure. However, bias may be unwittingly introduced by a single interviewer and a reflexive approach to the analysis was employed to mitigate this possibility. The study participants were already active in online communities, thus the findings may not be fully generalisable, although the authors recognise the rise in social media usage across all communities. The use of a modified IPA approach allowed for the data to be interpreted on several levels [51]. A mix of telephone and face-to-face interviews was conducted and potential differences introduced by this approach are acknowledged [52]. Detailed socio-economic data were not collected, and it is recognised that low income may affect access to mobile devices [53], is not thought to have prevented interviewees from participating in the discussion surrounding social media and apps usage per se.

In conclusion, social media appears particularly useful for people with RA. However, current apps to aid management of RA do not appear to fully meet patient needs. The development of a disease-specific app to track symptoms, store that information for future appointments [54], act as a resource for education, and importantly flexibility to link to existing social media platforms would be valued as part of a more patient-centred approach to clinical management.

Acknowledgements

We thank Arthritis Research UK and the National Rheumatoid Arthritis Society for assisting with recruitment and our participants for their time.

Financial Support: We thank the Worshipful Company of Curriers of the City of London for funding the study.

Conflict of Interest: None

References

1. NICE (2009) Rheumatoid arthritis: National clinical guideline for management and treatment in adults. National Institute of Clinical Excellence 2009.
2. Porth CM (2005) Disorders of Skeletal Function: Rheumatic disorders. In: Porth CM (7th Edn) Pathophysiology: Concepts of altered health states. Philadelphia: Lippincott Williams and Wilkins 2005: 1418-1419.
3. Katz PP (1998) Education and self-care activities among persons with rheumatoid arthritis. *Soc Sci Med* 46(10): 1057-1066.
4. Hakkinen A, Kautiainen H, Hannonen P, Ylinen J, Arkela-Kautiainen M (2005) Pain and joint mobility explain individual sub-dimensions of the health assessment questionnaire (HAQ) disability index in patients with rheumatoid arthritis. *Ann Rheum Dis* 64: 59-63.
5. Rupp I, Boshuizen HC, Dinant HJ, Jacobi CE, Van de Bos GA (2006) Disability and health-related quality of life among patients with rheumatoid arthritis: association with radiographic joint damage, disease activity, pain and depressive symptoms. *Scand J Rheumatol* 35: 175-181.
6. Azevedo AR, de Sousa HM, Monteiro JA, Lima AR (2015) Future perspectives of Smartphone applications for rheumatic diseases self-management. *Rheumatol* 35: 419-431.
7. Connelly LB, Woolf A, Brooks P (2006) Cost Effectiveness of interventions for musculoskeletal conditions. In: Jamison DT, Breman JG, Measham AR, Alleyne G, Claeson M, et al. *Disease Control Priorities in Development Countries*, (2nd edn) Musgrove. New York: Oxford University Press 2006: 963-980.
8. Berenbaum F (2014) The social (media) side to rheumatology. *Nature Rev Rheumatol* 10: 314-318.
9. Statista Number of social media users worldwide 2010-2021.
10. (2017) Office for Nation Statistics Internet access- households and individuals 2017.
11. Sarasohn-Kahn J (2008) The wisdom of patients: health care meets online social media. California Healthcare Foundation. Oakland, USA 2008.
12. Fox S (2011) The social life of health information, 2011. Pew Research Center's Internet & American Life Project. Washington D.C. USA 2011.
13. Kamel Boulos MN, Wheeler S (2007) The emerging Web 2.0 social software: enabling suite of sociable technologies in health and health-care education. *Health Info Libr J* 24: 2-23.
14. Ficarra B (2011) 3 reasons why social networking is not a waste of time for health professionals. *Health in 30 New York*. 21: 49.
15. Meroli M, Gray K, Martin-Sanchez F (2013) Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. *Journal of Biomedical Informatics* 46: 957-969.
16. (2000) Privacy Act: Implementation. *Fed Regist* 65: 82: 82462-82829.
17. Colineau N, C Paris (2010) Talking about your health to strangers: understanding the use of online social networks by patients. *Hew Review of Hypermedia and Multimedia* 16: 141-160.
18. Antheunis ML, Tates K, Neiboer TE (2013) Patients and health professionals use of social media in health care: Motives barriers and expectations. *Patient Education and Counselling* 92: 426-431.
19. Ludwig S (2012) Study: Mobile app usage grows 35%, TV & web not so much 2012.
20. Böhmer M, Hecht B, Schöning J, Krüger A, Bauer G (2011) Falling asleep with Angry Birds, Facebook and Kindle: a large scale study on mobile app usage. In: Proceedings of the 13th International Conference on Human Computer Interaction with Mobile Devices and Services (MobileHCI '11). ACM, New York, NY, USA 47-56.
21. Ventola CL (2014) Mobile devices and apps for health care professionals: uses and benefits. *P T* 39: 356-364.
22. Mosa AS, Yoo I, Sheets L (2012) A systematic review of healthcare applications for smartphones. *BMC Med Inform Decis Mak* 12: 67.
23. Quinn CC, Clough SS, Minor JM, Lender D, Okafor MC (2008) Well-Doc mobile diabetes management randomised controlled trial: change in clinical and behavioural outcomes and patient and physician satisfaction. *Diabetes Technol Ther* 10: 160-168.
24. Diabetes UK (2011) Diabetes UK Tracker App 2011.
25. (2015) ational Rheumatoid Arthritis Society: DAS tracker 2015.
26. Smith JA, Osborn M (2003) Interpretative phenomenological analysis, In: Smith JA (Edn) *Qualitative psychology: A practical guide to research methods*. London: Sage 2003: 53-80.
27. Smith JA, Flowers P, Osborn M (1997) What role does the body have in illness? Interpretative phenomenological analysis and the psychology of health and illness. In: Yardley L (Edn) *Material discourses of health and illness*. London: Routledge 1997: 68-91.
28. Bryman A (1988) Quality and quantity in social research. *Unwin Hyman, London* 1988: 44-70.
29. Boyle M, Harper DJ, Warner SJ (1993) Discourse, social constructionism and clinical psychology. *Change* 11: 72-79.

30. (2015) *Interpretative Phenomenological Approach*. University of London, Birbeck 2015.
31. Biggerstaff D, Thompson AR (2008) Interpretative Phenomenological Analysis (IPA): A qualitative methodology of choice in healthcare research. *Qual Res Psychol* 5: 214-224.
32. Turner AJ, Coyle A (2000) What does it mean to be a donor offspring? The identity experiences of adults conceived by donor insemination and the implications for counselling and therapy. *Hum Reprod* 15: 2041-2051.
33. Brocki JM, Wearden JA (2006) Critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health* 21: 87-108.
34. Kaiser K (2009) Protecting respondent confidentiality in qualitative research. *Qual Health Res* 19: 1632-1641.
35. Richards L, (1999) Data Alive! The thinking behind NVivo. *Qual Health Res* 9: 412-428.
36. Smith JA, Jarman M, Osborn M (1999) Doing interpretative phenomenological analysis. In: Chamberlain K, Murray M (Eds) *Qualitative health psychology: Theories and methods*, London: 218-240.
37. Finlay L (2008) A dance between the reduction and reflexivity: explicating the 'phenomenological psychological attitude'. *Journal of Phenomenological Psychology* 39: 1-32.
38. Collins K, Nicolson P (2002) The meaning of 'satisfaction' for people with dermatological problems: Reassessing approaches to qualitative health psychology research. *J Health Psychol* 7: 615-629.
39. Osborn M, Smith JA (1998) The personal experience of chronic benign lower back pain: An interpretative phenomenological analysis. *Br J Health Psychol* 3: 65-83.
40. Smith JA, Michie S, Stephansom M, Quarrell O (2002) Risk perception and decision making in candidates for genetic testing in Huntingdon's disease: An interpretative phenomenological analysis. *J Health Psychol* 7: 131-144.
41. Barlow J, Wright C, Sheasby J, Turner A, Ainsworth J (2002) Self-management approaches for people with chronic conditions: a review. *Patient Educ Couns* 48: 177-187.
42. Patrick K, Griswold WG, Raab F, Intille SS (2008) Health and the mobile phone. *Am J Prev Med* 35:177-181.
43. Mosa AS, Yoo I, Sheets L (2012) A systematic review of health-care applications for smartphones. *BMC Med Inform Decis Mak* 12: 67.
44. Rotheram-Borus MJ, Tomlinson M, Swendeman D, Lee A, Jones E (2012) Standardised functions for smartphone applications: examples from maternal and child health. *Int J Telemed Appl* 9: 32-37.
45. *Arthritis Care*
46. *Creaky Joints*
47. Azevedo R, Bernardes M, Fonseca J, Lima A (2015) Smartphone application for rheumatoid arthritis self-management: cross-sectional study revealed the usefulness, willingness to use and patients' needs. *Rheumatology Int* 35: 1675-1685.
48. Smolen JS, Breedveld FC, Burmester GR, Bykerk V, Dougados M, et al. (2016) Treating rheumatoid arthritis to target: 2014 update of the recommendations of an international task force. *Ann Rheum Dis* 75: 3-15.
49. Hootman JM, Macera CA, Ham SA, Helmick CG, Sniezek JE (2003) Physical activity levels among the general US adult population and in adults with and without arthritis. *Arthritis Rheum* 49: 129-135.
50. Rindfleisch JA, Muller D (2005) Diagnosis and management of rheumatoid arthritis. *Am Fam Physician* 72: 1037-1047.
51. Johnson JM (2002) In depth interviewing, *Handbook of interview research: Gubrium JF, Holstein JA (2002) Thousand Oaks USA: Sage 2002: 103-120.*
52. Smith JA (2004) Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qual Res Psychol* 1: 39-54.
53. Turner A, Barlow J, Ilbery A (2002) Play hurt, live hurt: living with and managing osteoarthritis from the perspective of ex-professional footballers. *J Health Psychol* 7: 285-301.
54. Wayne N, Ritvo P (2014) Smartphone-enabled health coach intervention for people with diabetes from a modest socioeconomic strata community: single-arm longitudinal feasibility study. *J Med Internet Res* 16: e149.