Comparing reactions to written leaflets, online information and real-time Doppler images among South Asian patients with rheumatoid arthritis

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Abstract

Objective
There is poor medication adherence in patients of South Asian origin with rheumatoid arthritis (RA). There is limited number of interventions to improve patient engagement. The objective of this study was to explore how patients of South Asian origin make sense of their disease after receiving written leaflets compared to online information or visualising real-time Doppler Ultrasound (DUS) images of their inflamed joints.

**Methods**

Patients of South Asian origin with RA were recruited from two NHS hospitals in the West Midlands, UK. In-depth semi-structured interviews were undertaken following exposure to vignettes designed to elicit patients’ perspectives on: (1) written leaflets, (2) online information to complement face-to-face interaction with healthcare professionals, and (3) DUS during the early stages of the disease journey. Data were analysed thematically until data saturation was reached in twenty individuals.

**Results**

The responses to vignette scenarios were described by patients: [1] perspectives on written leaflets during the early stages of the disease journey, [2] perspectives of online information to compliment face-to-face interaction with healthcare professionals, [3] perspective of DUS during the early stages of the disease journey. Overall, patients found real-time DUS more valuable in understanding RA and RA medications compared to other methods. Patients reported DUS reduced anxiety and helped address misconceptions about long-term disease and its ability to be controlled.

**Conclusion**

We have developed new understanding regarding the educational utility of a DUS session in patients of South Asian origin and how these sessions can be optimised to increase patient engagement and medication adherence.

**Key word:** Rheumatoid arthritis, RA, Doppler ultrasound scan, ethnicity, illness perceptions, medication adherence
Rheumatology Key messages

- This study proposes a novel intervention for improving clinical outcomes for RA patients of South Asian origin.

- The level of satisfaction with information received by a DUS session was linked with improved views about medicines and illness representations.

- The use of DUS as a means of providing biofeedback may prove superior to existing interventions with potential relevance to a range of conditions.
Introduction

Rheumatoid arthritis (RA) is a chronic systemic disease resulting in progressive joint damage, diminished quality of life, increased disability and premature mortality [1]. The treatment paradigm for RA has evolved over the past two decades, to earlier, more aggressive treatment with conventional synthetic disease-modifying anti-rheumatic drugs (cDMARDs), biologic DMARDs (bDMARDs) and targeted synthetic DMARDs (tsDMARDs)[1]. While improvements in disease activity and patient functional status mean that clinical remission is a realistic aim for most patients with RA, this is not necessarily true for all patient groups [2]. For example, South Asian patients originating from the Indian subcontinent, especially India and Pakistan, may have a disease framework centred on different illness perceptions and treatment beliefs [2]. We have previously shown this may have major implications for medication adherence [2, 3]. Moreover, we have also reported that patients of South Asian origin had significant delays in presenting to their primary care physician with RA symptoms - possibly due to lack of disease knowledge and cultural influences [4]. Recent novel work published by us has shown that patients of South Asian origin attending Early Arthritis Clinics demonstrated a disconnect with the treating healthcare professional, mainly due to lack of disease information and not having an opportunity to visualise their disease [5]. Yet, such clinics are major platforms for engaging patients in long-term disease management [6]. This may lead to poor medication adherence [5].

The fundamental question remains – how do we improve information delivery for patients of South Asian origin? [7, 8]. Educational interventions have shown promising results in improving medication adherence [8]. However, a review on interventions in RA highlighted that different types of interventions were required to optimise patient medication adherence and to encourage patient engagement. Intervention studies in RA have not included patients of South Asian origin. Moreover, written material not in an appropriate language may be a barrier to delivery of effective health-related messages [5].

In 2016, we published a potential approach that might assist clinicians to inform misconceptions about RA among patients of South Asian origin [9]. In that study, some patients reported that real-time imaging potentially increased understanding of RA and the role of RA medications. Joplin et al [10] also demonstrated that Doppler ultrasound (DUS) (Figure 1) might assist at improving medication adherence.
We therefore sought to explore how patients of South Asian origin make sense of their disease after receiving leaflets, or online information compared to visualising real-time DUS images of their inflamed joints. An explorative qualitative vignette [11] was used. Vignettes are short case stories about hypothetical characters in specified circumstances, to whose situation the interviewee is invited to respond [12]. The vignette technique is a method that can elicit perceptions, opinions, beliefs and attitudes from responses or comments to stories depicting scenarios and situations, and has been widely and effectively used [13].

**Methods**

Data have been reported in line with the Consolidated Criteria for Reporting Qualitative Research (COREQ) [14]. Patients originating from the South Asian continent were invited to participate in individual face-to-face semi-structured interviews. The term South Asian here applies to people from the Indian subcontinent, for example India and Pakistan [15]. Participants were recruited from two health Trusts in the West Midlands (central UK). Participants who had attended an initial clinic, had received a leaflet and undergone a DUS (Figure 1) within six months and clinician-diagnosed RA or other inflammatory arthritis were invited by clinical staff to participate in the study. Purposive sampling of participants was performed at Early Inflammatory Arthritis (EIA) clinics. Participants were recruited with a broad range of age, occupations and disease duration.

Written information outlining the study was sent to patients due to attend a follow-up EIA clinic appointment. A contact number for the researcher (KK) was provided if participants expressed interest in study participation. A mutually convenient interview time was arranged by the researcher with participants who agreed to participate. All participants provided written consent. KK has extensive experience in conducting qualitative research and is a female researcher of Indian background with fluency in English, Urdu and Punjabi. A pre-study questionnaire captured demographic data and disease activity score (Table 1). A vignette guide (Table 2) was developed based on discussions with the research team, including a patient research partner. It was suggested by our patient partner that it would be valuable to explore attitudes to other patient education material as well as DUS to better assess the impact of DUS. Thus, the vignettes included patients’ views on other formats of information such as leaflets and face-to-face.
The patient research partner was female and diagnosed with RA one year prior. Her experience of the EIA clinics, DUS session and living with the condition were valuable in developing the topic guide. Interviews followed an iterative process, with new concepts that emerged during data analysis explored in subsequent interviews. Each interview lasted approximately one hour, was digitally recorded, and transcribed verbatim. Transcripts were typed by an independent company familiar with translating material into different languages. Transcripts in Urdu and Punjabi were back translated into English by the company. The study was approved by the South Birmingham Research Ethics Committee [reference 251773].

Data analysis

Study data were analysed using thematic analysis, a method for identifying, analysing, and reporting patterns within data without trying to fit them into a pre-existing coding frame, or the researcher’s preconceptions [16]. For example, the researcher focused on patient partners’ suggested topics and concepts raised by patients during the interview were studied in detail. Each interview was analysed individually and compared with earlier or subsequent interviews to determine participants’ perspectives on DUS and delivery of information in EIA clinics. A multidisciplinary group with a range of expertise conducted data analysis. Two rheumatologists (PW and SR), a nurse researcher (CB-J) two health psychologists (CJA and SP) and a patient partner (BR) discussed the emerging analysis. This triangulation exercise allowed the team to view data from different perspectives. The patient research partner (BR) was able to reflect on the findings generated from this study and her past experiences of engaging with DUS sessions. Summarised findings were sent to study participants to see if they agreed with the conclusions. The first author (KK) analysed all the transcripts where data were subjected to line-by-line coding. The patient research partner independently coded three transcripts to develop reliable and inclusive patterns to each vignette informed by multiple perspectives. Step-by-step guidelines in qualitative data analysis were developed for the patient partner [17]. Discussion of the coding framework took place between the research team (KK, PW, SR, CB-J, and SP) and the patient research partner (BR). Coding categories that lacked concordance were discussed and absorbed into the coding framework. The initial codes were then grouped into the most noteworthy and frequently occurring categories. The core themes extracted and presented here focus on patients’ interaction with the DUS session and other mechanisms of information delivery (Table 3). Initially, the three predominant themes enhanced understanding of patients’ experiences with the DUS session.
Results

Of the thirty two patients approached to participate in the study, 12 declined due to time constraints. Twenty patients (12 females/8 males) agreed to participate in the study (age range 30-62 years). Mean disease duration ranged between six months to one year. Fifteen interviews were conducted in English, two in Urdu and three in Punjabi. Full quotes can be viewed in Table 4 and examples of representative quotes are presented at the end of each theme.

Patient perspectives of written leaflets during the early stages of the disease journey

In this study, only four patients reported finding information provided via written leaflets to be useful (Quote 1,2 and 3) during the early stages of the disease journey. Some patients struggled with reading, particularly non-English speaking patients and those with low literacy (Quote 4). Some patients admitted not receiving adequate information for self-management (Quote 5). Others felt that information provided via written leaflets failed to convey the severity of RA and did not help them to come to terms with the condition (Quote 5). Some patients reported written leaflets were less likely to provide them with an opportunity to engage with a chronic complex disease such as RA (Quote 4). Leaflets were also felt less likely to present the whole picture of RA, especially future consequences (Quotes 6 and 7).

Examples of patient quotes;

**Quote 1:** I think leaflets are good but more to know about rheumatoid I guess leaflets can be useful as a starting point. [Female, teacher, 30-years old, English-speaking]

**Quote 2:** I didn’t mind having leaflets to remind me of the problem. [Female, retired, 59- years old, English-speaking]

**Quote 3:** My leaflets had some information that I found useful on exercise but would prefer more to put thing into perspective. [Male, electrician, 32-years old, English-speaking]

**Quote 4:** I don’t rate leaflets to understand long term condition especially when you can’t read English. Most of the time everything is in English. I didn’t find mine useful [Female, homemaker, 62-years old, non-English speaking]

**Quote 5:** I read but it only scratches the surface for me and to be honest it doesn’t force me to self-manage nor did it help understand the severity. [Male gym instructor, 39-years old, English-speaking]
Patient perspectives of online information to complement face-to-face interaction with healthcare professionals

In this theme, patients expressed that additional verbal explanation about the condition together with online and leaflet information was beneficial (Quote 8). Many patients highlighted the personal approach of the clinician to be an important part of engagement (Quote 9). Patients expressed that not only was the explanation about the condition important, but the opportunity to change behaviour which facilitated better self-management of symptoms was also important (Quote 10). All patients expressed that their expectations after having a long-term condition diagnosed needed to be explained, and sometimes this was not done, given the limited time for consultation (Quote 11). Patients highlighted the need for additional information to be provided along with verbal communication (Quotes 12 and 13).

Examples of patient quotes;

Quote 8: you can really learn good lessons with health care team and the online material is also good. What this does is that it leaves you to deal with and make decisions yourself. [Female, retired, 59-years old, English-speaking]

Quote 9: the interaction that is half hearted is really not good for understanding the disease and treatments the approach of the doctor has to be right. I guess time is also a factor [Female, waitress, 46-years old, English-speaking]

Quote 10: My doctor does try to explain face to face is good but that message has to get into my head to understand what is going on and if there isn’t enough to change my behaviour then something more is needed. [Female, bank clerk, 57-years old, English-speaking]

Patient perspectives of Doppler ultrasound scanning during the early stages of the disease journey

In this theme, there were detailed explanations about the use of DUS. All patients interviewed in this study were positive towards having had a different method of education that helped them engage in understanding the disease process. Much of the data in this theme was linked to how patients perceived RA and the available treatments. The psychological impact was also evident.

Patients of South Asian origin found that having seen the DUS images with relevant explanation resulted in higher engagement levels with treatment (Quote 14). In particular, patients expressed a readiness to change, and adapt to self-management strategies after seeing the DUS images (Quotes 15, 16, and 17). Many views expressed by patients in the interviews related to increased motivation and a desire to be part of treatment decisions (Quotes 18 and 19). Personal attainment (benefits) was associated with increased knowledge and self-efficacy.
There was evidence highlighting how DUS assisted in informing their belief systems, allowing them to understand the necessity for medication, thereby enabling them to confidently take these agents (Quotes 18 and 19). Concerns decreased and were rationalised after the DUS session. Some patients felt that herbal remedies were sufficient to control RA symptoms. However after DUS, that view changed (Quotes 20 and 21). For some, it helped them come to terms with the chronicity of the condition, where patients reported a sense of acceptance sooner (Quotes 22 and 23). Patients expressed that their views on seeking a cure had also been altered after visualising their joints in the DUS session. Patients were more welcoming towards the control concept rather than expecting a “miracle” (Quotes 24, 25 and 26).

Patients commented that visualising their own joints via DUS helped reduce anxiety - since it helped them rationalise the problem. Many patients had a positive outlook towards the rheumatology service and looked forward to seeing their healthcare professionals. Moreover, many reported an improved relationship with their healthcare professionals following the DUS (Quotes 27, 28 and 29). There were positive views about DUS in helping them involve family members. Patients expressed that convincing family members in the Asian community about the severity of their arthritis posed a challenge, but that having DUS images provoked interest from family members and often led to increasing support for the patient. There were data that DUS helped balance the psychological impact of having a chronic condition in terms of managing fear and future consequences of RA (Quotes 30,31 and 32). Furthermore, there were views about the lack of awareness of RA among the South Asian community; patients felt this barrier could be broken by provision of copies of the DUS images (Quote 33).

Examples of patient quotes;

**Quote 14:** The direction of treatment can become much clearly to me and gave me much more engagement to manage myself. [Female, shop-keeper, 36-years old, English-speaking]

**Quote 15:** I will exercise my joints more freely because there was fear in my mind that if I move my joints I might make then worse. [Male, electrician, 32-years old, English-speaking]

**Quote 16:** I am doing more work at home and making my chapati. This scan reassured me that I am not doing any damage by moving my swollen joints. [Female, retired 61-years old, non-English speaking]
Discussion

This qualitative study explored the perspectives and experiences of receiving written leaflets versus online information compared to visualising real-time Doppler ultrasound (DUS) images of their inflamed joints in patients of South Asian origin with RA. It has demonstrated that symptom experience, illness perceptions (illness representation), perceived benefits/risks of treatment and the quality/quantity of information provided, influenced levels of patient engagement and medication adherence. We observed and document clear evidence that provision of real-time DUS images has given patients of South Asian origin an additional and possibly more effective platform from which to engage, than written leaflets or face-to-face consultation alone. This study highlights a potential platform for improving patients’ willingness to take long-term medication and an avenue for educating those with low health literacy.

We and others have previously reported that patient beliefs about treatment were grounded in necessity and concerns [18]. The notion of necessity in patients, who were informed of the need for therapy, derived from patient perceptions of illness, for example severity of symptoms stimulated medication use [19]. Therefore, the consequences of the condition and its controllability matched their expectations which out-weighed their concerns. Similar concepts have been reported in other diseases such as cardiology [20]. The way in which individuals judged treatment necessity was related to their concerns and lack of knowledge about RA. Moreover, as predicted by Horne et al, necessity beliefs were interlinked with perceptions of illness representations [21]. Our study found that patients of South Asian origin did not view RA symptoms to be serious initially. However, a DUS session helped to change that view and bought many to an earlier recognition of the importance of symptom control than leaflets alone. In contrast, the DUS session highlighted the importance and need for long-term therapy. There were also a few patients in this study who had high regard for traditional remedies and felt these could help improve RA symptoms. However, this perception altered after seeing DUS images. This would have been an unlikely outcome from leaflets and face-to-face discussion.

Of note, our study showed that patient perceptions about the need for treatment and decisions to continue treatment were reinforced by receiving adequate information, particularly real-time visual aids (DUS) in contrast to leaflet information. Work in other chronic diseases reported that patients with stronger treatment control beliefs were more likely to have better health status and be more likely to engage in self-care behaviours [21, 22]. The results of our study
demonstrated the ability of DUS to facilitate behavioural change. This may provide an opportunity to optimise clinical outcomes in patients of South Asian origin living with RA.

In non-RA diseases, interventions using real-time visual aids have been successful [10]. The utility of visualisation tools to engage patients in understanding their disease and treatment, and in reducing anxiety has been reported in other conditions such as vascular disease [23]. Moreover, a study of 207 European women with ovarian cancer [24] reported less anxiety and improved confidence and well-being following an ultrasound where they were showed images. Another study reported use of a moving three-dimensional heart in the context of an explanation of future risks of heart disease, had more impact on patients than text-based information alone [25]. In that study, twenty-three smokers attending a cardiovascular outpatient clinic were randomly allocated to one of two groups: to either receive a print-out of an ultrasound image of their carotid artery showing atherosclerotic plaque alongside an image of a disease-free artery, or to receive routine verbal feedback. This study reported effectiveness of personalized biomarker feedback to increase intention to stop smoking. The authors noted that the three-dimensional images of the heart increased patient understanding of heart disease risk, causal beliefs and control beliefs. Moreover, patients made more behavioural lifestyle changes, such as eating a healthy diet and taking up physical exercise in response to such images.

A Cochrane review of nine trials totalling 1371 patients looked at whether showing patients’ medical images of their problem would change behaviour towards external factors affecting disease outcome [26]. This review documented that visual feedback may help patients understand some contexts of the problem, for example the importance of smoking cessation, diet and healthy living. Some lifestyle factors that contribute to poor disease outcomes in RA patients are similar to those reported in this study, for example smoking, which is an important poor prognostic factor in RA. Building similar interventions in rheumatology might benefit patients, particularly those from ethnic backgrounds with lower health literacy. Extensive work in those with low health literacy suggests that educational interventions including leaflets and other formats such as online material have only resulted in a small change in increasing patients’ knowledge and were not successful at obtaining desired health outcomes[27]. Work around developing a handbook for patients only recruited non-South Asian patients – possibly limiting generalisability to those who could read [28]. The findings from our study are
encouraging and suggest that utilising DUS visual feedback within routine clinical practice may have a positive effect on treatment adherence and on overall disease management [29].

**Strengths and weaknesses**

Recruitment of South Asian patients was an important strength of this study, particularly the recruitment of male patients, as this patient group is often not included in studies. Although only 20 patients were enrolled, sufficient data were obtained for thematic saturation. Interviews were able to be performed in Urdu and Punjabi, ensuring meaning was accurately translated and cultural nuances preserved. Although the focus of the potential intervention was centred on South Asian patients, the opportunity for using visual or DUS representation in other ethnic populations could be considered; particularly among those with low literacy. A comparison between different minority ethnic populations requires further investigation.

**Conclusion**

This study has extended the evidence relating to the use of real-time DUS as a novel intervention for improving patient engagement and medication adherence in those of South Asian origin. Our results could be generalised to other ethnic minorities, or even to those from a low-literacy background. Engagement and adherence to treatment views were highly reported in patients who underwent DUS. In contrast, the more usual educative interventions using written leaflets or face-to-face consultations were not thought by patients to be as useful. The level of satisfaction with information received by a DUS session was linked with views about medicines and illness representations. Results from this study suggest that communication of information using DUS may be a novel and powerful intervention to improve medication adherence and correct patient misconceptions about RA.

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**Figure legend**

**Figure 1 Illustrating what doppler images display to patients**

Representative longitudinal views of the right third metacarpophalangeal joint (GE Logiq E, hockey stick transducer 8-18MHz) showing (a) metacarpal head (heavy arrow), synovitis/effusion (narrow white arrow) in greyscale, and (b) power Doppler signal (red) indicating increased vascularity in area of synovitis.
Table 1 showing demographic details of patients who took part in the study

| Patient no | Gender | Level of education | Age (years) | Type of Current Employment | DAS28-CRP around the time of interview | Treatment |
|------------|--------|--------------------|-------------|----------------------------|----------------------------------------|-----------|
| 1          | M      | University level   | 59          | Business                   | 3.8                                    | MTX       |
| 2          | F      | University level   | 30          | Teacher                    | 2.3                                    | SSZ and Pred |
| 3          | M      | University level   | 43          | Civil Servant              | 3.7                                    | MTX, HCQ  |
| 4          | M      | University level   | 32          | Electrician                | 3.0                                    | MTX, HCQ, Pred |
| 5          | M      | University level   | 42          | Manager                    | 4.5                                    | MTX, HCQ  |
| 6          | F      | Secondary school   | 57          | Bank Clerk                 | 2.7                                    | MTX       |
| 7          | F      | Secondary school   | 45          | Manager                    | 4.3                                    | MTX, HCQ, Pred |
| 8          | F      | University level   | 38          | Teacher                    | 3.4                                    | MTX       |
| 9          | F      | University level   | 34          | Police Officer             | 5.8                                    | MTX, SSZ  |
| 10         | M      | University level   | 39          | Gym instructor             | 3.3                                    | MTX, HCQ  |
| 11         | M      | Secondary school   | 35          | Construction Officer       | 3.3                                    | MTX, HCQ  |
| 12         | F      | Primary            | 43          | Home maker                 | 2.9                                    | MTX, HCQ  |
| 13         | F      | Primary            | 46          | Home maker                 | 3.4                                    | MTX, HCQ  |
| 14         | F      | University level   | 61          | Retired                    | 4.5                                    | MTX, HCQ  |
| 15         | M      | Secondary school   | 37          | Driver                     | 4.7                                    | MTX, HCQ  |
| 16         | F      | University level   | 59          | Retired                    | 2.2                                    | MTX, HCQ  |
| 17         | F      | University level   | 46          | Waitress                   | 3.4                                    | MTX, HCQ  |
| 18         | M      | Secondary school   | 43          | Technician                 | 5.6                                    | MTX, LEF, HCQ |
| 19         | F      | Secondary school   | 36          | Shopkeeper                 | 1.9                                    | MTX       |
| 20         | F      | Secondary school   | 62          | Home maker                 | 2.1                                    | MTX, HCQ  |

Foot note: MTX: methotrexate, SSZ: sulphasalazine, HCQ: hydroxychloroquine, Pred: prednisolone, LEF: leflunomide
DAS28 = Disease Activity Score

https://mc.manuscriptcentral.com/rheumap
Table 2 showing vignette scenario

Vignette 1 (receiving a patient information leaflet on your condition)
You are invited to the first clinic at the rheumatology department. Once your doctor has confirmed your diagnosis, he/she provides a written leaflet on your condition. Would this leaflet be enough to provide you with an understanding of your condition compared to visualising your joints?

Vignette 2 (face-to-face discussion and online resource)
You attended Rheumatology Clinic and your doctor or nurse discussed your condition and suggested to visit online resources for further information. How useful would this be to you compared to visualising your joints on screen during an ultrasound session?

Vignette 3 (seeing the swelling in joints on screen)
You are invited to have an ultrasound scan of your joints to see the amount of swelling in the joints. You get an opportunity to see the joints visually on the screen. What would be your thoughts? More questions around this during interview.
### Table 3 showing the thematic pattern of DUS and delivery of other information

|                          | **Leaflets**                        | **Weaknesses**                                                                 |
|--------------------------|-------------------------------------|-------------------------------------------------------------------------------|
| **Strengths**            | Can take away and read in own time  | Some understanding disease what does this mean?                                |
|                          |                                     | Lack of ability to justify disease seriousness                                 |
|                          |                                     | Not conveying the problem                                                     |
|                          |                                     | Reading things is different to seeing your joints in pain                       |
|                          |                                     | auto immune disease is not easy in a leaflet                                    |
|                          |                                     | problem for patients with literacy - language barrier                          |
|                          |                                     | family education – cannot not get involved                                     |
| **Face-to-Face and online** |                                     |                                                                               |
| **Strengths**            | Communication face to face good     | Time factor                                                                    |
|                          | Relationship                        | Face to face is good communication but the person might not tell you all that |
|                          | Rapport with doctor is important    | there is to be told                                                            |
|                          | Approach is important               |                                                                               |
| **Weaknesses**           |                                     |                                                                               |
|                          |                                     |                                                                               |
| **DUS**                  | Knowledge, satisfaction, informed choice, fear, extended consultation time, level of anxiety reduced, adherence, communication, source of evidence on severity, emotions – belief in controlling symptoms and sense of personal self-efficacy increase, seriousness of medication and disease, behaviour change, activity increase, lower literacy, meaningfulness, journey perspective , enlightenment, comprehensive, positive engagement with service, beliefs validation of symptoms | Nil reported                                                                  |
Table 4 showing patient quotes

| Patient perspectives of leaflets during the early stages of the disease journey |
|-----------------------------------------------------------------------------|
| **Quote 1:** I think leaflets are good but more to know about rheumatoid I guess leaflet scan be useful as a starting point. [Female, teacher, 30 years old] |
| **Quote 2:** I didn’t mind having leaflets to remind me of the problem. [Female, retired, 59 years old, English speaking] |
| **Quote 3:** My leaflets had some information that I found useful on exercise but would prefer more to put thing into perspective. [Male, electrician, 32 years old, English speaking] |
| **Quote 4:** I don’t rate leaflets to understand long term condition especially when you can’t read English. Most of the time everything is in English.[Female, home maker, 62 years old] |
| **Quote 5:** I read but it only scratches the surface for me and to be honest it doesn’t force me to self-manage nor did it help understand the severity. [Male gym instructor, 39] |
| **Quote 6:** These don’t do justice to get an understanding of this long time disease. With leaflets you browse through and don’t look at them again therefor you never really know the severity of the problem. The acceptance takes longer might be you do this after a long time. [Female, police officer, 34 years old] |
| **Quote 7:** I am slowly learning there is more to know with my condition if I had just been given a leaflet I would say that that wouldn’t be enough for me to fully engage with my condition. I feel more is needed to change the behaviour. [Male, driver, 37 years old] |

| Patient perspectives of online information to compliment face to face interaction with healthcare professionals |
|----------------------------------------------------------------------------------------------------------|
| **Quote 8:** you can really learn good lessons with health care team and the online material is also good. What this does is that it leaves you to deal with and make decisions yourself. [Female, retired, 59 years old] |
| **Quote 9:** the interaction that is half hearted is really not good for understanding the disease and treatments the approach of the doctor has to be right. I guess time is also a factor [Female, waitress, 46 years old] |
| **Quote 10:** My doctors does try to explain face to face is good but that message has to get into my head to understand what is going on and if there isn’t enough to change my behaviour then something more is needed. [Female, bank clerk, 57 years old] |
| **Quote 11:** Talking is good but not all doctors have time to explain things to you. Therefore less is spent on really meeting my expectations. The doctors need a new approach to educating patients.[Male, construction officer, 35 years old] |
| **Quote 12:** Talking face to face is good but if you have something better to add like these pictures then why not [Male, technician, 43] |
Quote 13: If the doctor is able to show me the problem then I would say that is much better can’t do that in just communication face to face. [Male, manager, 42 years old]

Patient perspectives of Doppler ultrasound scanning during the early stages of the disease journey

Quote 14: The direction of treatment can become much clearly to me and gave me much more engagement to manage myself. [Female, shop keeper, 36 years old]

Quote 15: I will exercise my joints more freely because there was fear in my mind that if I move my joints I might make then worse. [Male, electrician, 32 years old]

Quote 16: I am doing more work at home and making my chappiti. This scan reassured me that I am not doing any damage by moving my swollen joints. [Female, retired, 61 years old]

Quote 17: I am functioning on daily basis the last time I had the scan there wasn’t much on my joints so everything is going in the right direction I am going for walks. [Male, own, business, 59 years old]

Quote 18: my level of motivation to take medication has increased and I will take my medication. [Female, teacher, 38 years old]

Quote 19: time has changed now and the desire to more about what is going on is increasing my public. This has given me a good way to know more for myself. I am more confident at work. [Male, civil servant, 43 years old]

Quote 20: Seeing the scan makes you realise how difficult it is to control the problem if medication isn’t taken Asians it takes time to convince of the problem scan does this. [Male, driver, 37 years old]

Quote 21: My thinking was this was not a serious disease saw a lot swelling on the scan picture. I can take my medication now with an aim I mean more meaningfully. [Female, home maker, 43 years old]

Quote 22: I would be thinking that ginger and methi [herbs] will help and not take medication properly but I am working with my doctor now to see there is a lot swelling. [Female, retired, 61 years old]

Quote 23: the thought did cross my mind to try herbal stuff but after seeing the pictures may be not a good idea and to try the medications first. [Male, manager, 43 years old]

Quote 24: if this scan wasn’t shown to me I would have gone on about whether to or not accept this condition. Everyone has this period where we presented nothing is going on but seeing the scan made me realise the problem and I guess I had to make myself understand. [Female, bank clear, 57 years old]

Quote 25: I would have been in denial about this but I know now why I need to take physio as well. [Female, retied, 59 years old]
Quote 26: At the start of all this I was thinking how serious can this be, but after seeing the scan I knew that this is all about control and no cure. [Female, home maker, 62 years old]

Quote 27: the doctor told me that there wasn’t going to be any cure on this yet and to be honest after seeing the joints and swelling I can believe there wasn’t going to be any miracle. [Female, home maker, 43 years old]

Quote 28: The fear of starting the problem then we have the fear of starting treatment then the fear of future and for women fear of coping with family life and disease. At least with seeing the pictures you can reduce some of that anxiety. [Female, teacher, 38 years old]

Quote 29: I look forward to coming back to the hospital appointment. This has given me a different feeling towards managing my condition. [Female, shop keeper, 36 years old]

Quote 30: I feel very positive towards my doctor and my relationship is much better if I only had leaflets then I wouldn’t be so keen. [Male, manger, 42 years old]

Quote 31: I was really pleased that my daughter came with me to the scan and she saw my joints as well it felt like my whole family would get an insight into this now because it can be isolating to live with a long term disease. [Female, home maker, 43 years old]

Quote 32: when I first started off with the problem my mental state was really bad I was getting upset after seeing the scans of my joints I thought I could balance my mental state and work with the doctors my perception was altered. [Female, shop keeper, 36 years]

Quote 33: The awareness of the disease in our community is not that much I realise this is a serious problem. I think new technology will help break that barrier. [Female, retied, 59 years old]
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