**The accessibility and usability of an Australian web-based self-management programme for people with lower health literacy and joint pain in the UK: a qualitative interview study**

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**Key words:** Health literacy, low health literacy, self-management

**Introduction**

Osteoarthritis (OA) is a widespread and disabling degenerative joint disease associated with significant pain [Arthritis research UK 2013]. People with OA should be provided with self-management strategies to promote healthy lifestyles and maintain function [Pinto et al 2012, OA National clinical Guidelines 2008,Clark et al 1991]. The success of self-management education is not equitable for all patient groups [Lowe et al 2013]. Often health information is too complex for patients to understand [Rowlands et al 2015]. People’s ability to access, understand and use health care information is influenced by health literacy and this impacts health outcomes [Sorensen et al 2012]. Clinicians repeatedly over estimate patient’s health literacy and this may impact on the poorer outcomes already experienced by patients with lower literacy [Rowlands et al 2015, Smith et al 2013,Berkman et al 2011, Loke et al 2012]

The shift towards a Digital NHS alongside increased internet usage [Zajac et al 2012], provides opportunities for e-health self- management approaches. However, web based health information is not always accessible for people with lower literacy levels [Chapman et al in press].

MyJointPain (MJP) ([www.myjointpain.org.au)](http://www.myjointpain.org.au)) is a free, web based self-management resource for people with OA, created by Arthritis Australia in partnership with patients, it can be tailored to monitor self-reported physical and psychological needs. MyJointPain is effective in an Australian population [Umapthy et al 2015] and has some evidence of applicability in the UK [Alego et al 2017]. However, it is not yet known how accessible the resource is for people with lower health literacy. This study explored the facilitators, barriers and experiences of people with self-reported joint pain and low health literacy when accessing and utilising the “My Joint Pain” website.

**Methods**

Following full ethical approval (ethics no 20070); participants were recruited from general social groups organised by the local council in community centres in inner city locations that were ranked as within the UK’s poorest 5%. Participants were eligible to participant if they scored ≥2 on a 5 point ordinal score from 1=Never, 2=Rarely,3=Sometimes, 4=Often, 5=Always in response to the Single item literacy screener (SILS) question *"How often do you need to have someone help you when you read instructions, pamphlets, or other written material from your doctor or pharmacy?"* [Morris et al 2006]; and ≤23 on the Short Test of Functional Health Literacy for Adults (S-TOFHLA) [Parker et al 1995], were over 18, reported joint pain ≥3 months and had daily access to a computer, broadband internet and an email account. The study used a phenomenological approach to gain insight into the lived experiences of participants. This approach allowed participants the freedom to describe their experiences and allows the opportunity to seek clarification and deeper understanding whist preserving context.

*Procedure*The researcher gave a study presentation to the community groups. Expression of interest forms were completed by participants and screening consent gained. If eligible, full written informed consent was gained and a demographic questionnaire completed. Participants were asked to use the MyJointPain website for two weeks. They were invited to take part in a semi structured interview that had been designed and checked for content and face validity with professional peers by the researchers (Appendix A). Interviews were conducted by the first author and lasted approximately 8 minutes. All participants elected to have the interview conducted in their own homes but were offered a community location.

*Data coding and analysis*Interviews were digitally recorded and transcribed verbatim. Thematic analysis was completed using Braun and Clarke’s framework [Braun and Clarke 2006] and NVivo software [NVivo 2012]. Data analysis was carried out by the first author and independently verified by the second author. Any disagreements were discussed until consensus was achieved. Respondent validation was offered but all participants declined.

**Findings**

Six participants (1 Male, 5 Female) with a mean age of 46.6 years (SD14.48); mean SILS of 3 and a mean S-TOFHLA 17(SD 2.73) were recruited and assigned pseudonyms (Table1).

|  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- |
|  | Hanna | Yvonne  | Neil | Ann | Louise | Yazmin |
| Sex | Female | Female | Male | Female | Female | Female |
| Age  | 50 | 51 | 54 | 74 | 58 | 25 |
| Highest level of education | FE College | Secondary School | Secondary School | Secondary School | Secondary School | FE College |
| SILS | 3 | 3 | 3 | 3 | 3 | 3 |
| S-TOFHLA | 20 | 22 | 14 | 22 | 20 | 21 |

(Table 1. Participant characteristics and health literacy scores)

**Abbreviations**: Single item literacy screener (SILS) , Short test of functional health literacy for adults (S-TOFHLA) Scoring values: Inadequate functional health literacy = 0-16; Marginal functional health literacy = 17-22; Adequate functional health literacy =23-36. Further education college (FE College)

Thematic analysis identified four key themes;

1. Dealing with technical issues
2. Information overprovision
3. Motivations for information seeking
4. Desire for OA specific professional input
5. ***Dealing with technical issues***

All participants experienced technical challenges accessing MJP. Yvonne attempted to access the website repetitively and worked around the log in process.

*‘****I tried several times****…****I just got onto it eventually without the screening****’* (Yvonne, L12-13, S-TOFHLA 22).

Similarly, Louise persevered and used a different email address.

 ‘***I tried logging on with two different email addresses’***(Louise, L17, S-TOFHLA 20)

Whereas Neil looked to his family network to help

***‘I Couldn’t get onto it straightaway****,* ***I had to get my daughter to actually login****’* (Neil, L10, S-TOFHLA 14)

All participants actively sought a solution. Participants were not deterred by technical difficulties and displayed self-motivation and perseverance.

***2 Information Over provision***

Participants felt that the depth and volume of information was excessive and, at times, overwhelming.

***‘I thought it was a bit,******probably over the top****‘* (Neil, L35, S-TOFHLA 14)

MJP information was viewed as complex and text heavy;

***‘there was just too much to go through…it was really hard to sort of go through it all and find what I needed find out’*** (Yvonne, L53-54, S-TOFHLA 22)

This impacted engagement with the health messages provided. Hanna relates how she lost her concentration with the volume of text;

*‘…****you lose concentration******and then you lose where you are and your understanding of what you’re trying to read’* …..*some of it got a little bit deep where I couldn’t really understand what it was telling me. Errm again I just skip that bit****’* (Hanna, L56-57, S-TOFHLA 20)

Yazmin felt that the volume of text indicated that MJP was mainly relevant for people who already have knowledge and experience of joint pain;

***‘I wouldn’t recommend it to someone who doesn’t have the backgroun****d’* (Yazmin, L78-79, S-TOFHLA 21)

For Louise, less information was appealing, and tailored information was even better;

*‘…****look at whereabouts you are in treatment******and what sort of knowledge you’ve got****…* ***so whether you wanted things in detail you can actually say you wanted the detail’***(Louise, L59-60, S-TOFHLA 20)

***3 Motivation for information seeking***

The inclusion of videos of people with whom the participants could relate was identified as helpful and facilitated understanding; Hanna recounts;

 *‘****when you see something it’s easy to understand******and and to relate to your own problems rather than reading something because******you can’t always marry the two up’…***

For Hanna, it was important to see credible examples of how others have coped; examples from others in similar situations were persuasive;

*‘…****people who are actually going through it,******that would be helpful because they’d understand more… it would be more beneficial from people who actually suffer the pain…they would also be able to give us tips and little things that they’ve learnt themselves****’* (Hanna, L142-145, S-TOFHLA 20)

Pain reduction was a significant driver for our participants seeking information.

*‘****Specifically****,* ***I was looking for something to obviously ease my pain, that’s what I was looking for’*** (Hanna, L90, L105-106, S-TOFHLA 20)

 ***‘I couldn’t find the the the******information on the pain and how to control the pain****.*’ (Neil, L24-25, S-TOFHLA 14)

Participants were also aware of strategies that they could use to manage joint pain;

***‘I should be making more of an effort******to maybe go swimming errm and maybe even just walking up to the top of the road’***(Ann, L47-49, S-TOFHLA 22)

and were pleased to see efforts reaffirmed on the website;

*‘[I]found reading about the weight interesting because I go to slimming world so it was* ***reaffirming what they have said to me***(Ann, L43-44, S-TOFHLA 22)

Whilst Louise felt the website provided credible reassurance that she was not damaging her joints;

 ***‘confirming that what I was doing was not wrong and that’s nice. Its umm put my mind at ease****’* (Louise, L90-91, S-TOFHLA 20)

MJP offered hope and reassurance that joint pain could be actively managed

***‘that you know there is help out there for the pain…******the pain can be helped****’* (Ann, L90-91, S-TOFHLA 22)

***4 Desire for osteoarthritis specific professional input***

Participants identified that engagement with professionals with knowledge of joint pain should be integral to digital e health approaches.

Face to face interactions with health professionals were reassuring and offered opportunities to ask questions.

***‘I think you have it from the health care******where the healthcare are telling you and explaining to you what your problem is****’* (Hanna, L141-142, S-TOFHLA 20)

Neil’s doubts that an online self-management resource could meet all his needs confirmed this;

*‘I think* ***you need more hands-on than sort of being told*** *[information]’* (Neil, L55, S-TOFHLA 14)

And Ann identified the importance of personal contact to help continue to motivate her;

*‘****without somebody taking an interest******in me it’s very very difficult to keep the spirit up enough to be motivated****’* (Ann, L21-22, S-TOFHLA 22)

**Discussion**

This project explored the experiences and feelings of people with joint pain and lower levels of health literacy when using an e-health self-management resource. Findings indicate that individuals are willing and able to access web based resources to manage their joint pain and were motivated to engage with the information providing it was clear, included images of relatable situations and had the ongoing support of a health professional. Simple, clear messages with images supported participant engagement.

These results indicate there is still discrepancy between the depth and coverage of health information provided .Health literacy has a significant impact on self-management behaviours [Ishikawa and Yano 2008] and our findings confirm that provision of health information is often too complicated for universal understanding [Lowe et al 2013, Coulter and Ellins 2007, Chapman et al accepted in press]. Our results add further evidence to research about the impact of disengagement with health advice when the message is unclear [Ware et al 2013]. As with other research our participants were over whelmed with the volume of information [Houts et al 2006]. This is particularly pertinent as people with lower health literacy can lose motivation to engage when information is too complex [Parker 2000].

Our research suggests that people have difficulty extrapolating and interpreting information As with previous studies [Katz, Kripalani and Weiss 2006, Austin et al 1995, Leiner et al 2004, Delp and Jones 1996] our participants confirmed that images and videos with which they could identify improved engagement[Filippatou and Pumfrey 1996] and adherence to self-management strategies [Hosey, Freeman and Stacqualursi 1990, Chinn 2011].

Our participants were more likely to engage with ‘things you can do at home’ suggesting that self-management must be specific [Marino, Simoni and Silverstein 1991, Van Uden-Krann et al 2008, Eysenbach 2004]. Social and peer support is known to improve self-management [Kelleher 1991, Marino, Simoni and Silverstein 1991, Van Uden-Krann et al 2008, Eysenbach 2004] and the development of an online forum may be an option for future improvement.

 Our study has limitations; the small sample may mean that data saturation was not achieved, technical difficulties prevented some participants accessing some areas of the website and usage time was not monitored potentially impacting the richness of experiences. We collected demographic data (Appendix B) and whilst no participant reported more than two painful joints in, it is not possible to rule out fibromyalgia as opposed to osteoarthritis as a cause of participant joint pain. Further encouragement and support for harder to reach groups to join our research patient and public involvement team may have been useful for interview schedule development.

*4.2 Conclusions*

Our participants’ have provided insight into key areas for consideration when providing e-health self-management resources for people with lower health literacy.

Further effort to involve harder to reach groups when designing self- management resources should serve to make these resources accessible to all users. Text volume, detail and use of images should be carefully considered. E-Health self-management resources may play a valuable part in supporting people to manage joint pain on a daily basis. Our findings suggest that personal contact with a knowledgeable health professional is highly valued and sought after.

**References**
Algeo, N., Hunter, D., Cahill, A., Dickson, C., & Adams, J. (2017). Usability of a digital self-management website for people with osteoarthritis: A UK patient and public involvement study. International Journal of Therapy and Rehabilitation, 24(2), 78-82

Arthritis Reasearch UK, Osteoarthritis in General Practice, (2013).

Austin, P.E., Matlack, R., Dunn, K.A., Kesler, C., Brown, C.K. (1995). Discharge instructions: do illustrations help our patients understand them?, Annals of Emergency Medicine. 25; 317–320.

Berkman, N.D., Sheridan, S.L., Donahue, K.E., Halpern, D.J., Crotty, K. (2011). Low health literacy and health. outcomes: an updated systematic review. Ann Intern Med. 19; 155(2):97 107.

Braun, V., Clarke, V. (2006). Using thematic analysis in psychology, Qualitative Research in Psychology. 3; 77–101.

Chapman, L., Brooks, C., Lawson, J., Russell, C., and Adams, J. The accessibility of online self-management support websites for people with osteoarthritis: a text content analysis. Chronic Illness. Accepted In press

Chinn, D. (2011). Critical health literacy: A review and critical analysis, Social Science & Medicine. 73; 60–67.

Clark, N.M., Becker, M.H., Janz, N.K., Lorig, K., Rakowski, V., Anderson, L. (1991). Self-Management of Chronic Disease in Older Adults, Journal of Aging and Health. 3; 3–27.

Coulter, A. and Ellins, J. (2007). Effectiveness of strategies for informing, educating, and involving patients, Bmj. 335; 24–27

Delp, C., Jones, J. (1996). Communicating information to patients: the use of cartoon illustrations to improve comprehension of instructions, Academic Emergency Medicine. 3; 264-270

Eysenbach .(2004). Health related virtual communities and electronic support groups: systematic review of the effects of online peer to peer interactions, BMJ. 328; 1166–0.

Filippatou, D. and Pumfrey, P.D (1996). Pictures, titles, reading accuracy and reading comprehension: a research review (1973‐95), Educational Research 38 (3); 259-291

Hosey, G.M., Freeman, W.L.,Stracqualursi, F., (1990). Designing and evaluating diabetes education material for American Indians, Diabetes education 16(5):407-14

Houts, P.S., Doak, C.C., Doak, L.G., Loscalzo, M.J. (2006). The role of pictures in improving health communication: a review of research on attention, comprehension, recall, and adherence., Patient Educ Couns. 61; 173–90.

Ishikawa, H. and Yano, E. (2008). Patient health literacy and participation in the health-care process, Health Expectations. 11; 113–122.

Katz, Kripalani, Weiss,. (2006). Use of pictorial aids in medication instructions: A review of the literature, American Journal of Health-System Pharmacy. 63; 2391–2397.

Kelleher, D.J. (1991). Patients learning from each other: self-help groups for people with diabetes., Journal of the Royal Society of Medicine. 84; 595-597

Leiner, M., Handal, G., Williams, D. (2004). Patient communication: a multidisciplinary approach using animated cartoons, Health Education Research. 19; 591-595

Loke, Y., Hinz, I., Wang, X., Rowlands, G., Scott, D., Salter, C. (2012). Impact of Health Literacy in Patients with Chronic Musculoskeletal Disease–Systematic Review PLoS genetics. 7(7):e40210

Lowe, W., Ballinger, C., Protheroe, J., Lueddeke, J., Nutbeam, D., Armstrong, R. (2013). Effectiveness of musculoskeletal education interventions in people with low literacy levels: a systematic review., Arthritis Care & Research. 65; 1976–85.

Marino, P., Simoni, J., Silverstein, L. (2007). Peer Support to Promote Medication Adherence Among People Living with HIV/AIDS, Social Work in Health Care. 45; 67–80.

Morris, N.S., MacLean C.D., Chew L.D., Littenberg B. (2006). The Single Item Literacy Screener: Evaluation of a brief instrument to identify limited reading ability. BMC Family Practice. 7; 21. doi:10.1186/1471-2296-7-21.

NVivo qualitative data analysis Software; QSR International Pty Ltd. Version 10, 2012.

Osteoarthritis (2008) national clinical guidelines for care and management in adults

Parker, R.M. (2000). Health literacy: a challenge for American patients and their health care providers, Health Promotion International. 15; 277–283.

Parker, R.M., Baker, D. W., Williams, M.V., Nurss, J.R. (1995). The test of functional health literacy in adults: a new instrument for measuring patients' literacy skills. J Gen Intern Med.10(10); 537–541.

Pinto, D., Robertson, C., Hansen, P., Abbott, H. (2012). Cost-Effectiveness of Nonpharmacologic, Nonsurgical Interventions for Hip and/or Knee Osteoarthritis: Systematic Review, Value in Health. 15; 1–12.

Rowlands, G., Protheroe, J., Winkley, J., Richardson, M., Seed, P. T., Rudd, R. A. (2015). Mismatch between population health literacy and the complexity of health information: an observational study. Br J Gen Pract. 65(635) e379-e386.

Smith, S.G., Curtis, L.M., Wardle, J., von Wagner, C., Wolf, M.S. (2013). Skill set or mind set? Associations between health literacy, patient activation and health. PloS one. 8(9):e74373

Sørensen, K., Den Broucke, S., Fullam, J., Doyle, G., Pelikan, J., Slonska, Z. (2012). Health literacy and public health: a systematic review and integration of definitions and models., BMC Public Health. 12; 80.

Umapathy, H., Bennell, K., Dickson, C., Dobson, F., Fransen, M., Jones, G. (2015). The Web-Based Osteoarthritis Management Resource My Joint Pain Improves Quality of Care: A Quasi-Experimental Study., Journal of Medical Internet Research. 17, e167.

Van Uden-Kraan, Drossaert, Taal, Shaw, Seydel and Van de Laar. (2008). Empowering Processes and Outcomes of Participation in Online Support Groups for Patients With Breast Cancer, Arthritis, or Fibromyalgia, Qualitative Health Research. 18;405–417.

Ware, N.C., Wyatt, M.A., Geng, E.H., Kaaya, S.F., Agbaji, O.O. (2013). Toward an understanding of disengagement from HIV treatment and care in sub-Saharan Africa: a qualitative study, PLoS Med. 10, discussion e1001369

Zajac, I., Flight, I., Wilson, C., Turnbull, D., Cole, S., Young, G. (2012). Internet usage and openness to internet-delivered health information among Australian adults aged over 50 years., Australas Med J. 5; 262–7.

**Tables**

|  |  |  |  |  |  |  |
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