

The 'virtual' reality of life with a long-term condition: exploring online discussion boards as a reflection of self-management policy in practice

Caroline Sanders, Anne Kennedy,
Caroline Gardner, Anne Rogers
NPCRDC, University of Manchester



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Background

- Increased use of internet as a resource for people with LTCs
- Use varies e.g. age, gender, class
- Potential forum for extending formal self-management training
- Expert Patients Programme (EPP) adapted for online
- EPP sessions include: exercise, nutrition, sleep, medications, communication, emotion management, cognitive techniques



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Methods & Analysis

- Analysis of web postings for 11 classes (218 participants, class size 12 - 24)
- Individual postings, multiple responses and threads
- Data entered into Access database
- Codes, comments and memos created within Atlas.ti



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Data

- Analysing posts to:
 - Discussion board (difficult emotions, celebrations)
 - Problem board (prompted by 'problem' topics introduced each week to be 'solved' through posts from participants)
 - Action plans and suggestions for overcoming barriers



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Sharon, you are in the Discussion Centre (DEMO)

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Self Care Online in the NHS • epp.online@nhsepp.org

Discussion Centre / Discussion Topics

Welcome to Discussion Topics



Discussion Topics

Select a Topic

How do I get started?
 You are in the Discussion Centre. Select one of the topics from the selection and click the "Go" button. You should visit the Discussion Centre several times a week.

MENU

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Learning Centre / Session 2

Dealing with Difficult Emotions

This week we would like to explore with you how your living with an ongoing health problem makes you feel difficult emotions such as frustration, worry, anger, fear, or whatever you name other types of difficult emotions.

First, identify how you feel using no more than one or two words like "angry", "worried", "concerned", "depressed", etc. Second, think about what is causing you to feel this emotion. Finally, write down your emotion and the reason(s) in the box below. Everyone expresses these feelings in different ways, don't worry if you can't find the exact words to describe your feelings. Click the "show me" button for examples. [Show Me!](#)

I feel when :

If you find that you have a lot to write, you may want to continue this exercise in the **Diary** section of **My Stuff**. Also during the week, go to the **Discussion Centre** two or three times to read messages for the Difficult Emotions discussion topic. Give suggestion to others, and see what they have to say to you.

Next, we will be discussing a technique that can break the Symptom Cycle at many different points - exercise.

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Profile of EPP participants

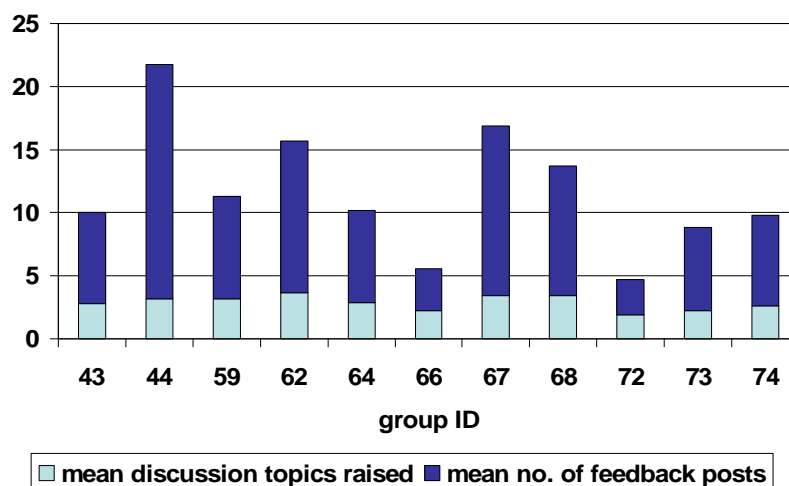
	Online	Community
Female	77%	70%
Age < 45 years	49%	17%
Full time employment	38%	(20% RCT)
Degree/prof qual	55%	34%
Live alone	17%	27%
Non white ethnicity	6%	5%
Arthritis	28%	35%
Rural location	67%	(30% RCT)



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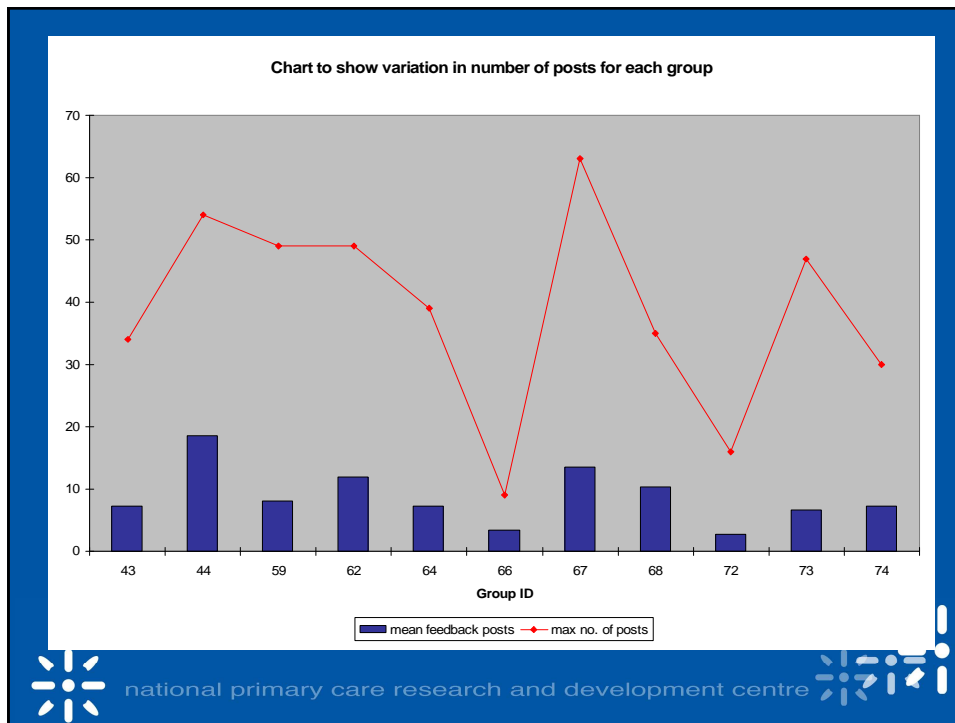


chart to show degree of participation per group



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Social support & EPP online

- I dont feel so isolated in regards to i have common symtoms and dificulties with other people on this EPP course[...] It has ben a tremendous relief to be in touch with others who understand the difficulties. It has given me encouragement to do something about the difficulties and not to be afraid of things like the depression i currently have. (ID 1352, class 66, W, chronic fatigue syndrome (CFS))
- Meeting all the lovely people on line and sharing has been the best [...] The course was of no benefit with my particular situation and unfortunately with the NHS's financial crisis there is no light at the end of this tunnel.(ID1273, class 62, W, arthritis & diabetes)
- 869, the sharing for me has been a big part. Instead of using the ears of friends and families and Doctors. We've used each others ears, but instead of bending them. it seems we have supported each other.(ID 878, class 44, W, chronic back problems)



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The course, online support and 'real life' (class 43)

- I don't know how much longer I can cope with my current situation [...] When I read X's posting about feeling suicidal, I really feel that we all have a common link [...] I'm also disappointed that this course doesn't seem to understand my predicament and makes me feel inadequate. I cannot always keep up with the work and cannot exercise at all, nothing, nada, zilch. I can just about drag myself a few yards to the stairlift for the loo and usually wet my pants on the way, yet you should see the exercise plan they have sent me! Crazy! I'm doing this course online BECAUSE I can't move. (ID835, W, genetic condition affecting joints, skin & organs)
- I hope you do get some help soon :) Re: the course & exercise: if you can't do it, then don't. The suggested exercises were totally silly for me as well. (ID842, W, ME/CFS)



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- Hi 835, I feel quite upset reading your entry. I wish I could help more [...] I've admitted to feeling fear about the future and as you stated about 849s posting feelings of being out of control of your condition can become overpowering I have rang the Samaritans, Usually during the night when I cant sleep and its `really dark` [...] So maybe we do at times have a common link. As for the course I agree with 842. Warm thoughts 835 (ID848, W, MS)
- I am so sorry that you are feeling so bad [...] No one can understand any condition fully unless they have it themselves [...] I totally understand what you are feeling and I wish there was more I could do to help you other than just being able to relate. I know from my own condition that I get very upset with the people who don't understand [...] I found it very helpful to get in contact with other people who have my condition through the internet [...] Do you think this is something you might consider, take care, 827 (ID827, W, Lupus)



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- 842, 848, 830 and 827, thank you so much. We all have so many overlapping symptoms so responses from you actually mean something because I know when you say you understand, you really do. I will take many of your suggestions on board... The Samaritans was something that I had thought wasn't for me as I wasn't actually phoning with pills or razor blades in my hand, but if they are there to just to talk through these sort of feelings as well then thats really very helpful... I know a little about Lupus, so I realise what your mountain is all about and the ME, MS and multiple forms of arthritis and general debilitating side issues of pain and fatigue that we all share makes us a formidable bunch when it comes to hands on advice. So blow the exercise plan, just for the time being and the beating myself up about it and I'll listen to you guys, because we have all been there. (ID835)



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Real life and social isolation

- I feel scared and sad when I am alone all day. I have a care worker that comes in, but I really don't want to see her, yet I cry a lot when I am alone. I actually feel lonely and not sure why. I can fill my time and have lots I can/should do, but don't want to do it alone at this point in time. I actually liked being on a hospital ward recently because of the company but felt tragic when I had no visitors. Pathetic [...] I used to have such a large hub of family and friends and work colleagues and social life when I was working and well. Now I have moved to the country and have tried but hardly know any like minded people and my family have all died or gone away. My husband is really great and has been home for the last two weeks and I'm dreading him going back to work tomorrow. (ID 835)



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Problems of 'real' relationships

- today I have to go over my parents and meet up with the rest of the family for a family meal. However the journey over there hurts me to the extreme and when Im there they think that half of the time I am making it up, which really hurts. (they dont understand the concepts of chronic pain) This has a knock on effect as I feel negative thoughts which in turn makes my pain even worse [...] When it comes to taking my tablets I always do that in private so my family dont have to see it [...] As I said my day went as expected, I put on a brave face and struggled through the day in pain. I smiled when I had to, and said the right things when I had to [...] The day is nearly now over and my back is killing me. I have got 3 hot water bottles on my back in the hope to relieve some of my pain and relax the nerves in my back a bit. I hope what I have just said makes some sense and is not all gobally gook, its just that my pain level is high and I was hoping to visit the site for a bit of moral support. (ID 1255, class 62, M, chronic back pain, MH/ depression)



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Managing illness in a family context

- I feel angry when my family assume that just because I have a good day or part of a day that I could be like that every day if I "really wanted to" (ID 1313, class 64, W, MH/ depression)
- Tutor: I wonder if it would help for you to provide your family with some information about your condition and the affects it has [...]
- Thanks Mod2 but what is the best way to provide the information? I have tried printing out stuff from the internet but they just don't seem to take it in or relate it to me and them. My [...health worker] is happy to talk to my husband but it all seems to go over his head and come back to whether I am contributing financially to the family. Today was so awful!! [goes on to describe a significant event for one of her children that she found stressful, financial difficulties she was helping her children with, taking a loan, looking after her grandchild so her daughter could work...] the whole family is screwed up one way or another and I can't hold it together on my own anymore!!!!...



HELP!!!!!!!!!!!!!!!!!!!!!!!!!!!!!! (ID 1313)

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Non-participation (Class 44)

- Responses made to criticisms of non-participation:
 - Hi Everyone, I don't think you can make people contribute if they don't want to. I accept that they know what is involved when they sign up, but it is my experience with forums that a lot of people prefer to sit on the sidelines reading the posts but not contributing. This may seem unfair but so long as we all get something from the course surely thats all that matters? (ID 877, W, joint problems and depression)
 - Hi I think that you are being a bit critical as those of us who haven't used any sort of discussion forum before may find it harder to participate due to the relevance we feel of what we have to say and the reaction we may get to our post's this doesn't mean that we aren't HERE and I personally have read EVERY post in EVERY room just because I dont always reply doesn't mean that I am not participating in my own way. Sorry if this had turned in to a rant but I felt that it needed to be said. (ID 857, W, Rheumatoid arthritis)



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Gender

- Hi 1255, It is possible to feel isolated even when there are people all around [...] It is sometimes easier to talk about these things to non-family members/close friends (ID 1252, class 62, W, eye disease)
- ...1252 I now and appreciate what you mean by someone to talk to however I find it okay typing in to this keypad but Im unsure if its a bloke thing but I couldnt or would find it really difficult to physically sit down face to face and talk about my emotions. I guess at the moment I will stick to playing games on the Internet and hopefully visiting a site or two for a chat. (ID 1255, class 62, M, chronic back pain, MH/ depression)
- Sorry to all for the delay - the main thing i have learned is not to bottle up my feelings or problems. (ID 1518, class74, M, diabetes)



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Discussion

- Policy assumptions do not necessarily accord with 'real life'
- EPP online may be fulfilling previously unmet needs for social support (especially emotional) for this select group
- Discussion boards as a 'window' on 'real' life especially experience of illness in family context
- Gender issues and non-participation
- The future of online research and interventions?



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