the institute of mental health
Nottingham
research excellence for innovation

Online peer support: the evidence and good practice

28th November 2014

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On behalf of
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The University of Nottingham
UNITED KINGDOM · CHINA · MALAYSIA

Introductions

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Part 1

ONLINE SUPPORT COMMUNITIES: WHAT, WHY AND HOW?

Internet use in the UK

In 2014, 38 million adults (76%) accessed the Internet everyday

The nature of Internet access continues to change

- 58% smart phone
- 43% portable computer

22 million (84%) households have Internet access, compared with 57% in 2006

Source: Office for National Statistics [www.ons.gov.uk] – August 7 2014 bulletin

Internet use for health purposes

Ziebland et al., (2004)

A qualitative study of Internet use by patients living with cancer

175 men and women aged 19-83 years, with one of five cancers (prostate, testicular, breast, cervical, or bowel) diagnosed since 1992 and selected to include different stages of treatment and follow up

Before visiting their doctor **-** To discover the possible meaning of symptoms

During investigations - To seek reassurance that the doctor is doing the right tests, to prepare for results, to improve the value of the consultation

After the diagnosis - To gather information about the cancer (including information that is "difficult" to ask about directly), to seek advice about how to tell children, to contact online support groups, to seek second opinions, to make sense of the stages of the disease, to interpret what health professionals have said, to tackle isolation

When choosing treatments - Information about treatment options and side effects, experimental treatments, research, and alternative and complementary treatments

Before treatment - To find out what to take to hospital, what will happen, what it will be like, what to expect of recovery, how to identify and to prepare questions to ask the doctors

Short term follow up - Information about side effects, reassurance about symptoms, advice about diet, complementary treatments, advice on benefits and finances, to check that the treatment was optimal, perceived therapeutic benefits

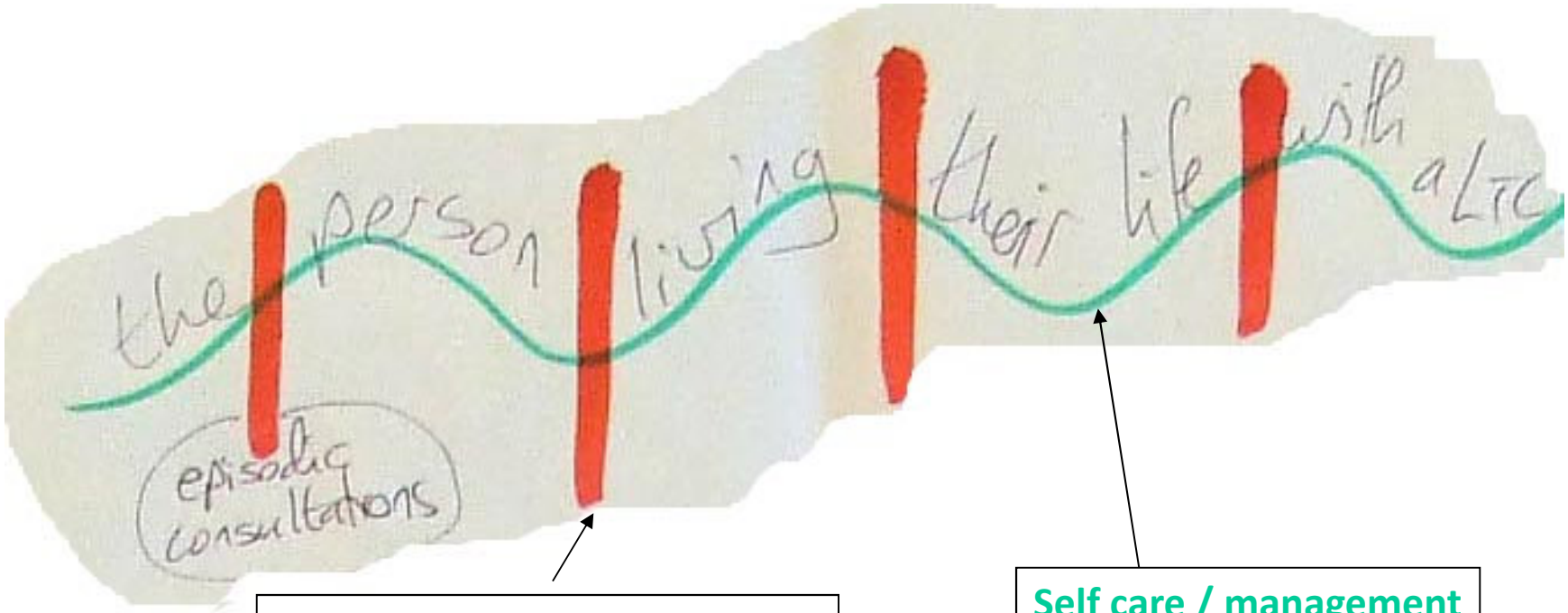
Long term follow up - To share experience and advice, contact support groups and chat rooms, to campaign about the condition, to make anonymous inquiries

Who do patients listen to?

messages transmitted via peers are *more credible*
(A rapid review of the current state of knowledge regarding lay-led self-management of chronic illness DH *Evidence review December 2005*)

"Patients often lack relevant information and often feel disempowered by this. The power imbalance between clinician and patient can make patients reluctant to explore issues of concern to them. But informal sources of information are trusted more and encourage self caring behaviours with greater consistency."

The reality: The individual's perspective



The potential of the Internet for peer support

- In the past 10 years, we have seen an explosion of patient support tools (e.g. self-assessment), interventions (e.g. self-management) and information online (e.g. websites)

- Peer-to-peer **connection** has become increasingly popular
  - Social Networking Sites (e.g. Facebook)
  - Twitter
  - Blogging

- Online equivalent of something that has been happening in the face-to-face world for many years

Online peer support communities

- "...a group of individuals with similar or common health related interests and predominantly non-professional backgrounds (patients, health consumers, informal caregivers) who interact and communicate publicly through a computer communication network such as the internet (…) allowing social networks to build over a distance"

[Eysenbach et al., 2004]

What types of online peer support communities are available to the public?

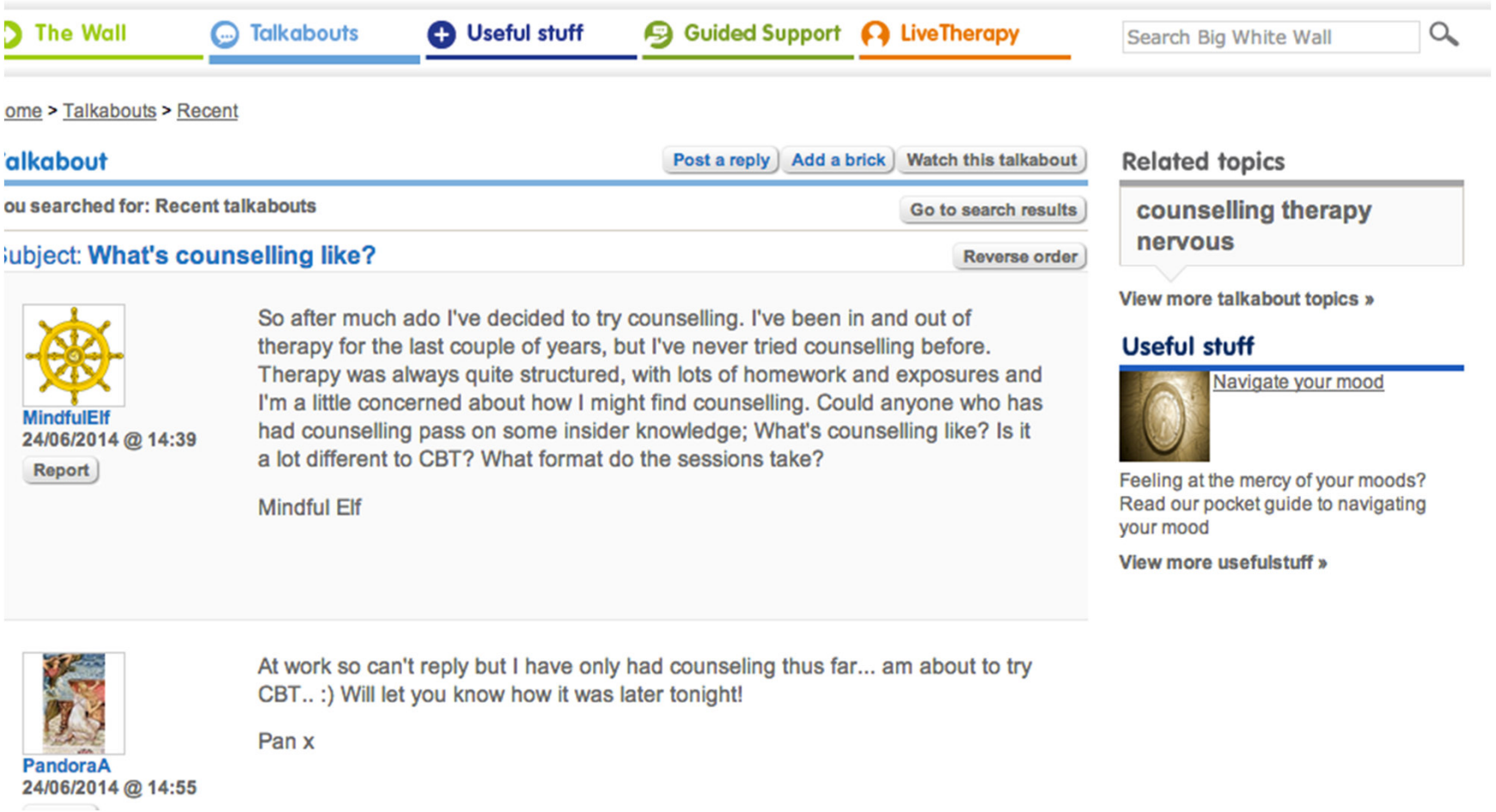
- **Asynchronous**
  - Individuals are not online at the same time
  - Popular examples: discussion forums, mailing lists

- **Synchronous**
  - Individuals are present at the same time online
  - Popular examples: chat rooms

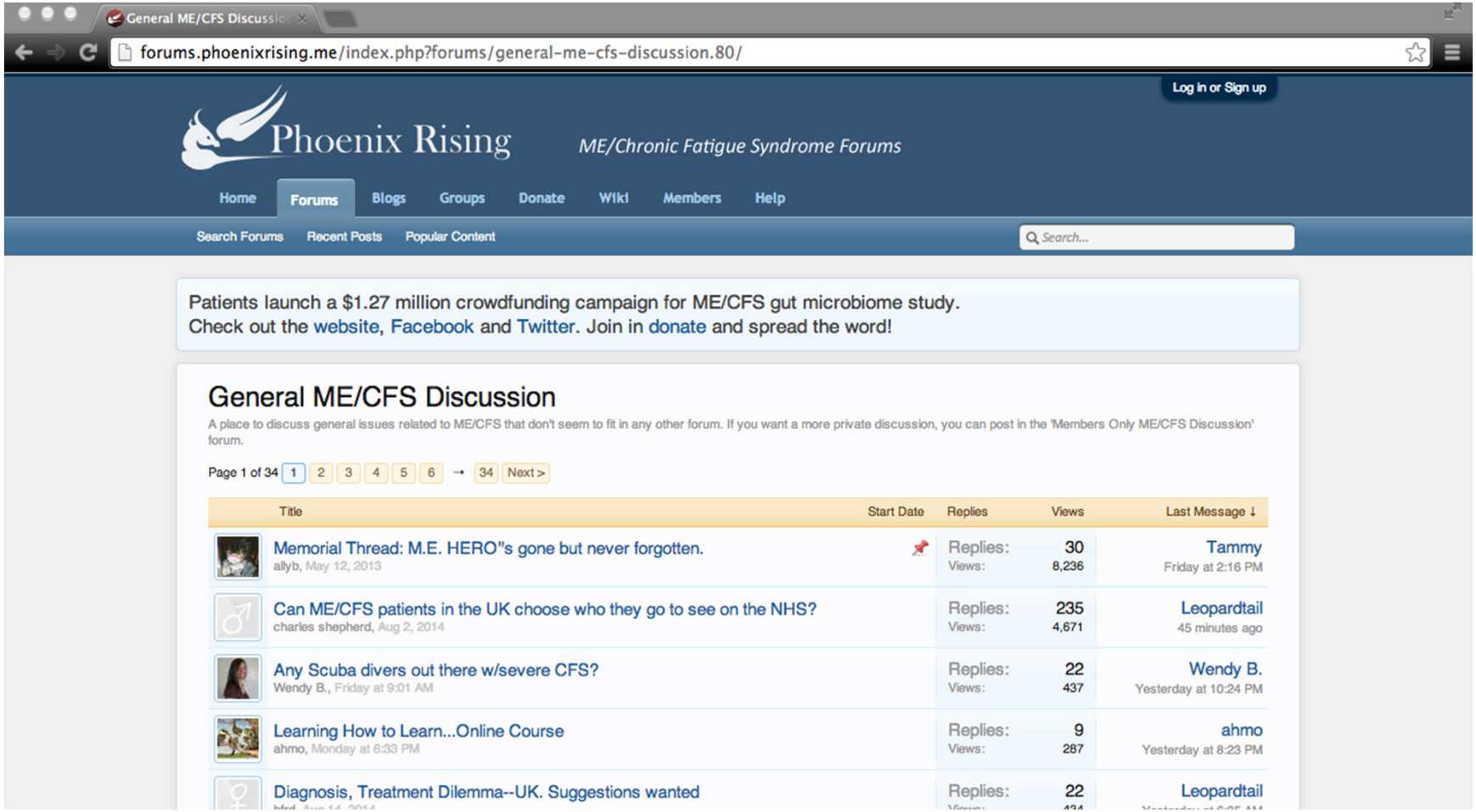
- (Many) moderated by a health professional or patient?

- Many self-management tools and interventions have a peer support community embedded within in them

Big White Wall



Phoenix Rising

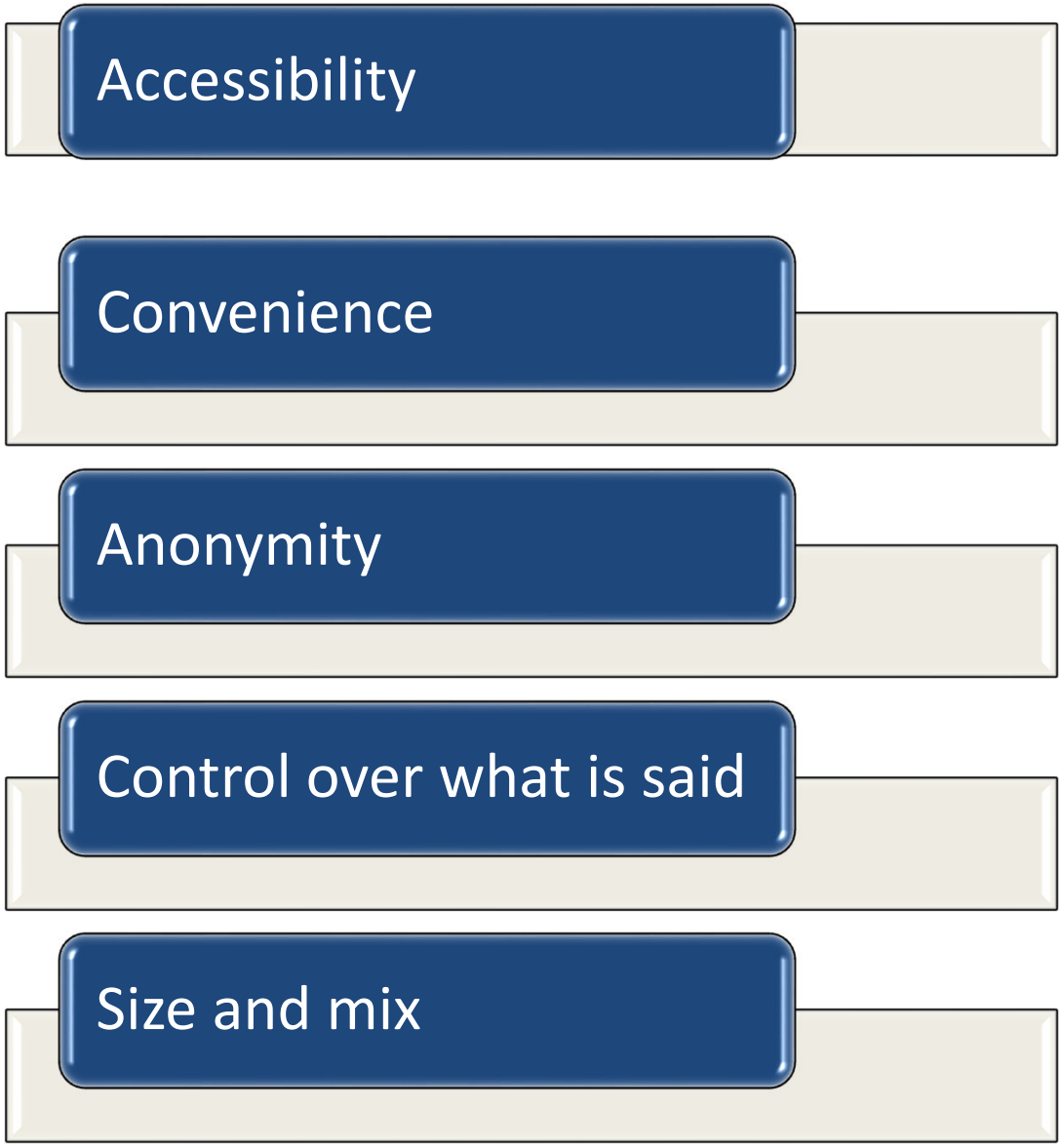


Unique characteristics

Increasingly popular with patients and the public

1. Patient interviews and surveys (both offline and online)
2. Analysis of the online discourse
3. Awareness of the social media landscape

Various chronic conditions have been researched



Why do people engage with online peer support communities?

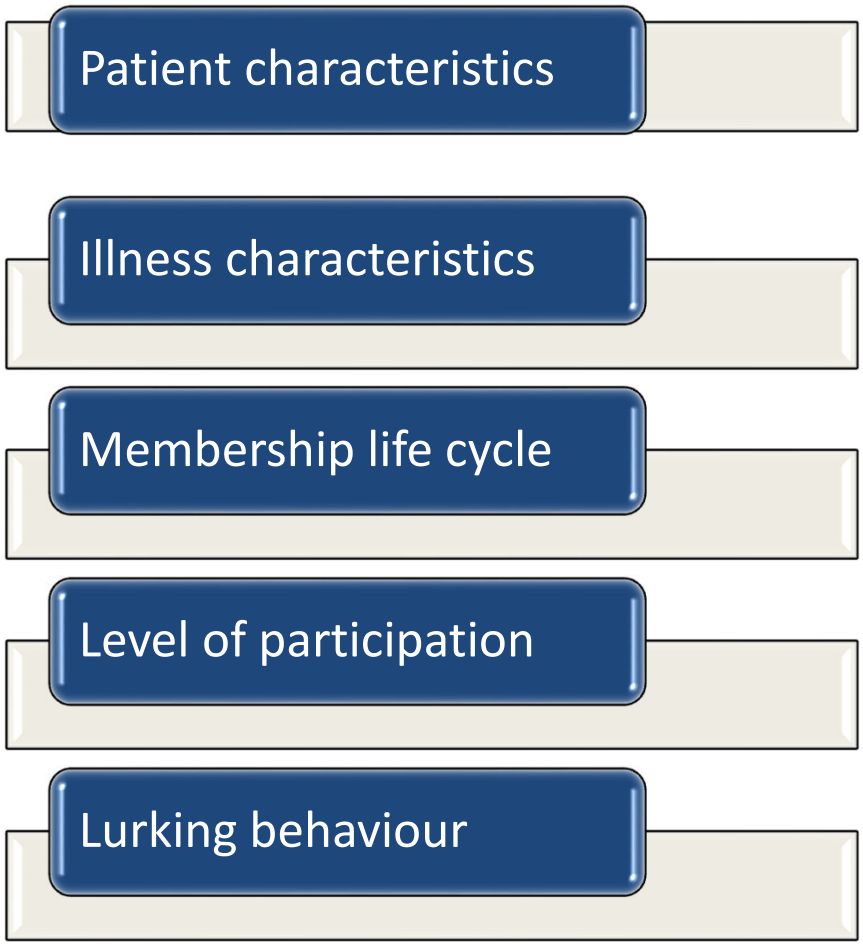
Table 1.
Reasons for accessing an IBD online support community.

Reason	*No. of participants*	*% of total*
To find others in a similar situation	201	80.7
To learn new information about my condition	165	66.3
To share experiences	162	65.1
To share information with others	146	58.6
To find emotional support	142	57.0
To seek advice	140	56.2
To offer support to others	135	54.2
To ask a question about my condition	128	51.4
Because it was convenient	107	43.0
Because it was available 24/7	90	36.1
Because I was feeling lonely	77	30.9
To understand medical terminology better	65	26.1
Because of an increase in the severity of symptoms	64	25.7
Because I was experiencing new symptoms	50	20.1

Note: Participants could endorse more than one reason.

Coulson, N.S. (2013). How do online patient support communities affect the experience of Inflammatory Bowel Disease. JRSM Short Reports, 4, 1-8.

Characteristics associated with participation



- There are many different factors that are associated with participation but these are the most commonly discussed within the literature

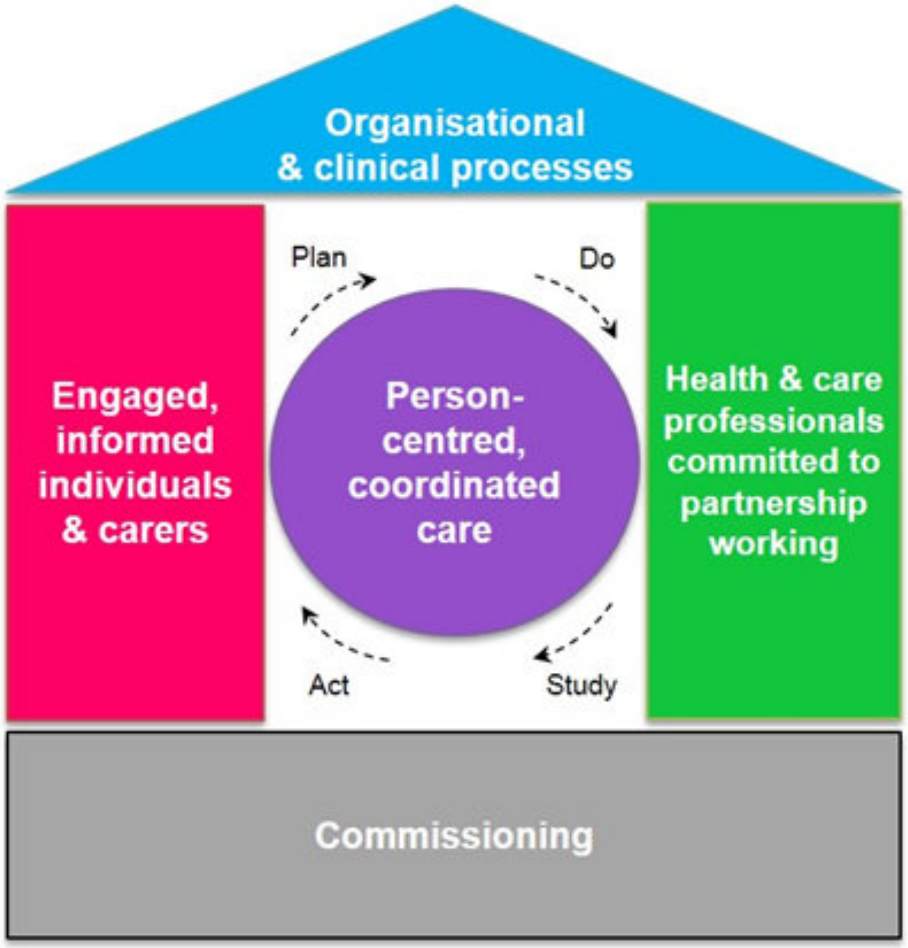
- Surveys, interviews, focus groups both online and offiline

Patient characteristics

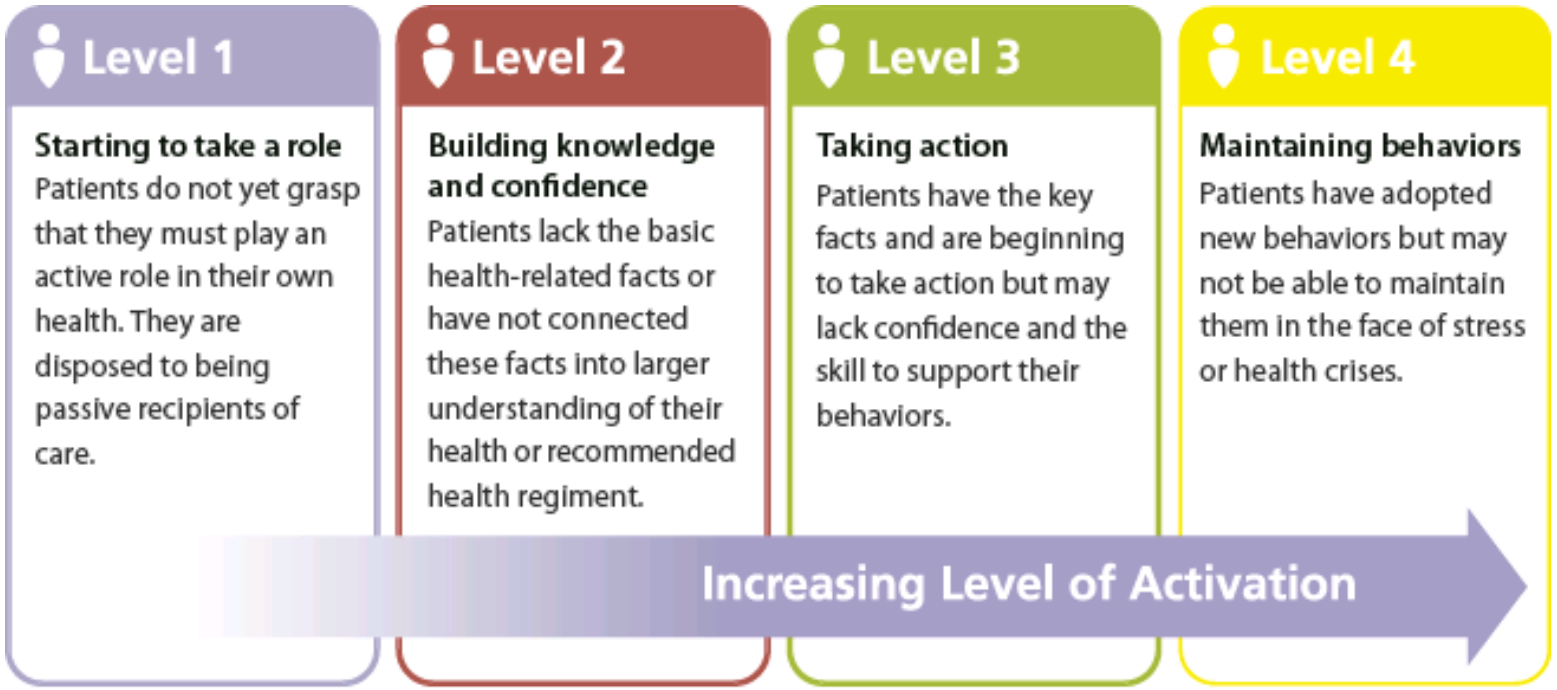
- People seeking health-related information and support online tend to be:
  - White, female, well-educated, younger and employed
  - Higher socio-economic status
- The association between patient's demographic characteristics and health-related Internet use may reflect barriers to Internet access among certain groups of people.

- Shaw et al., (2006)
  - Provided free Internet access, computer hardware and IT training
  - Demographic barriers reduced BUT some psychosocial factors were found to predict engagement (e.g. breast-cancer worry, relationship with doctor)
- Overall, not a lot of research that has explored psychosocial characteristics and use of online support communities

House of Care model



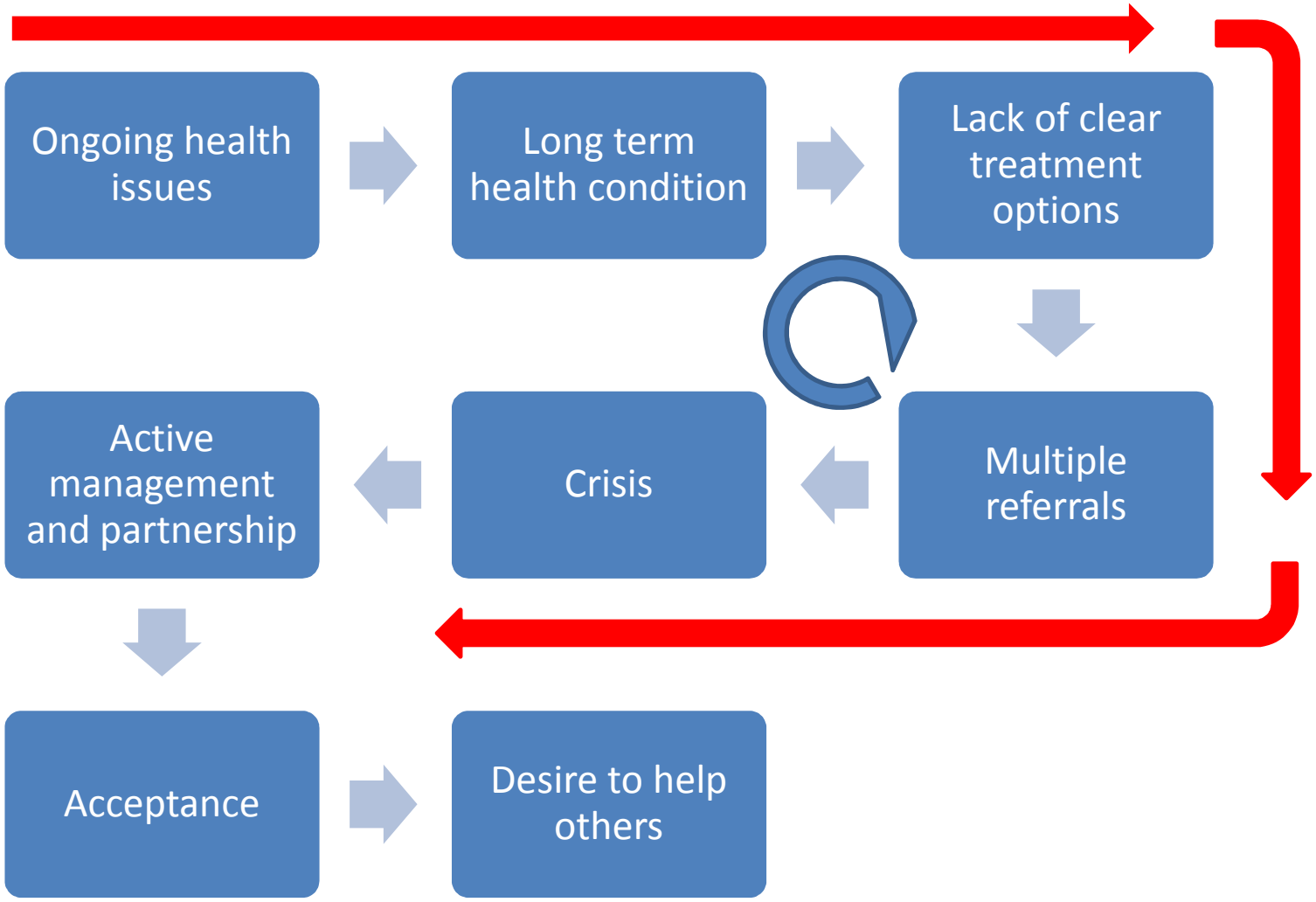
Here we describe the **House of Care model** – its origin and application. The House has arisen out of a need to change the way we deal with long term conditions. The sheer scale of the LTC challenge for modern healthcare systems means that we need a paradigm shift – away from the 'medical model' of illness (which worked efficiently in



Need to understand persons current level of health competency and build from there

Source: Prof Judy Hibbard, University of Oregon

From passive to activated



Illness characteristics

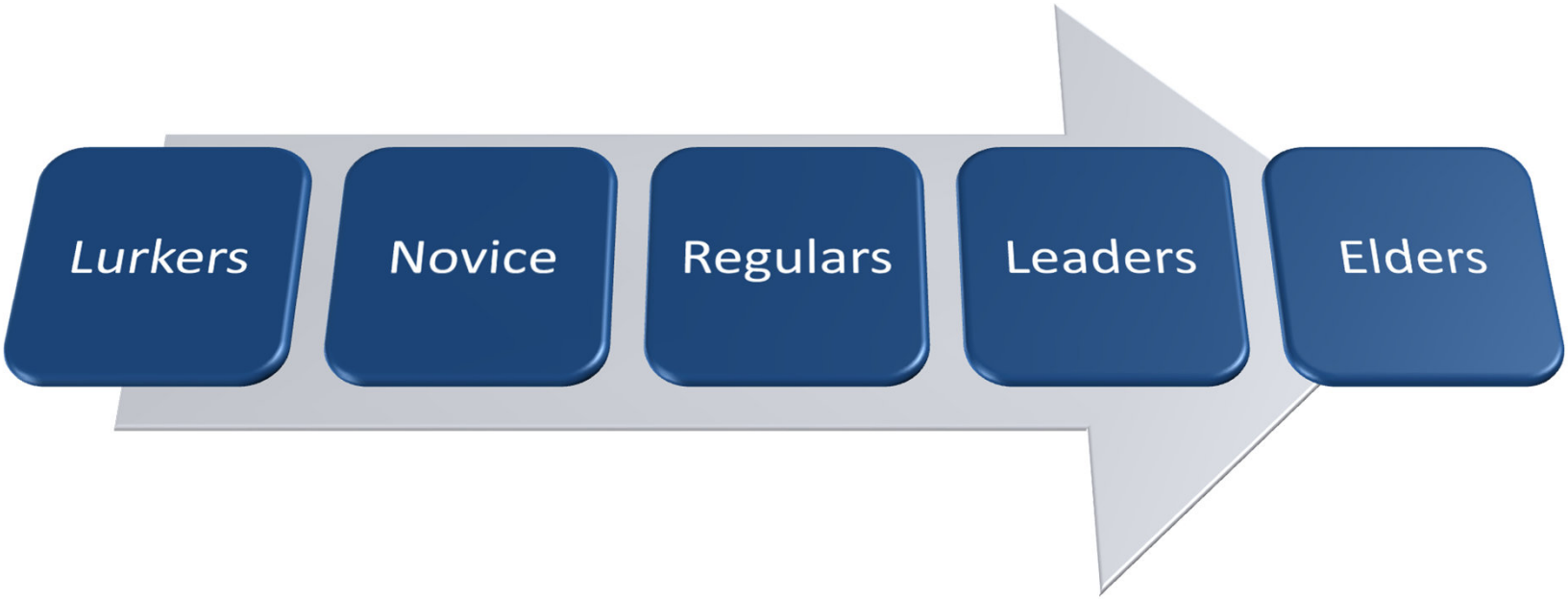
- Diseases with fewer treatment options and conditions with an unclear aetiology, which are poorly understood by the medical profession, appear to be particularly common online (Ferguson, 1996)

- Furthermore, research suggests that conditions described as embarrassing or socially stigmatising, are also associated with higher levels of Internet support behaviour (Davison, Pennebaker & Dickerson, 2000).

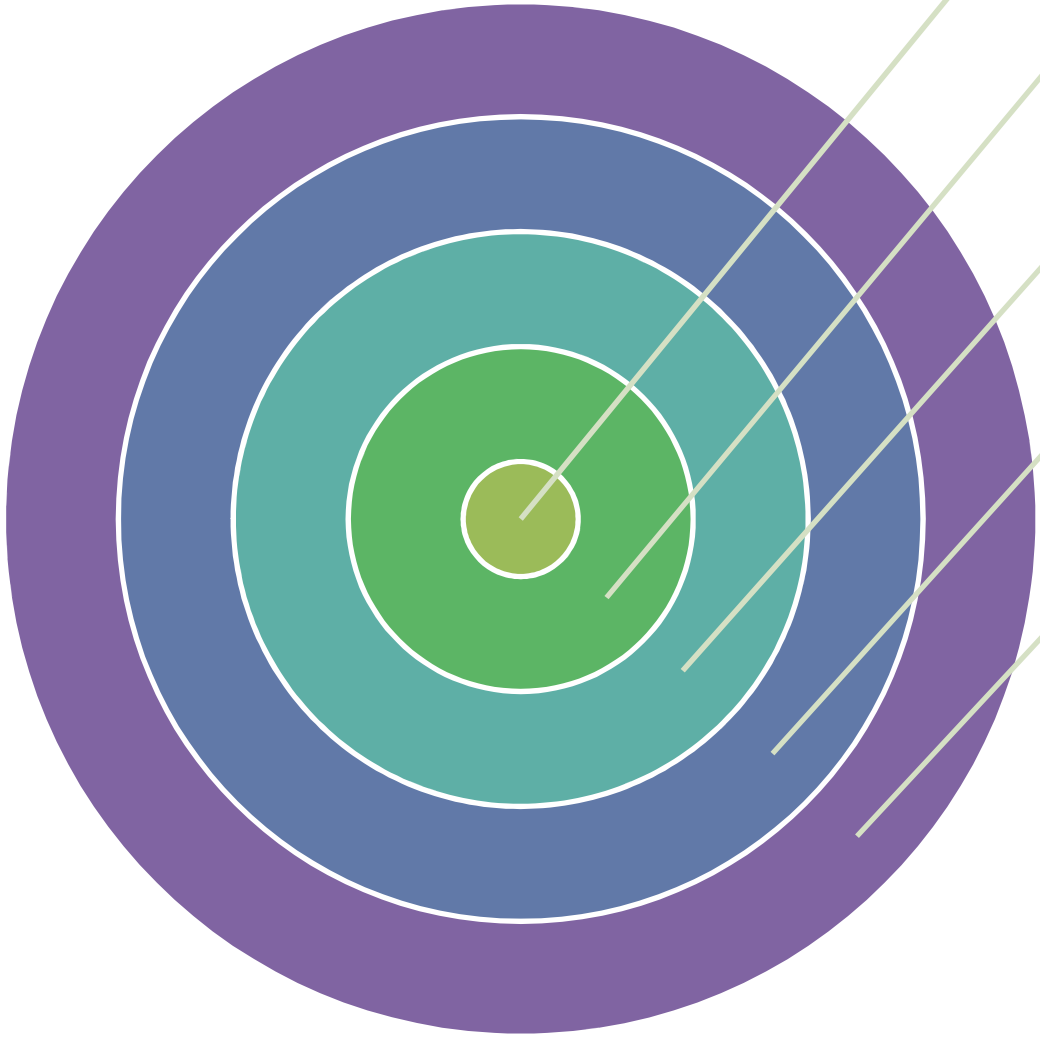
- Indeed, diseases such as cancer and HIV/ AIDS are particularly prevalent online, whereas support communities for conditions like heart disease and stroke are less common.

- Many forums devoted to supporting those with mental health problems

Membership life cycle (Kim, 2000)



Levels of Involvement



Leader/ coordinator

Willing helpers - 1

Willing helpers - 2

Regular attenders

Visitors in crisis

Silent Members

Free-riders

Face to Face Levels of Involvement

- **Leader/or leaders /coordinator / s:** This role will vary from a democratic chair to stronger leadership control.
- **Willing helpers:** This includes those who take on greater responsibilities through a committee (level 1) and those who help by making tea, moving chairs etc (level 2).
- **Regular attenders**: These come to meetings but are unwilling or unable to take on more responsibility.
- **Visitors in crisis**: These may come for one or two meetings or may stay for several months then move on. They get what they need from the group to help in a crisis – may be better to refer to occasional visitors as not all are in crisis – eg.some are young people who don't want to get too involved but still have some need to attend / get info
- **Silent members**: These do not come to meetings but value the newsletter etc.
- **Free-riders**: These do not come to many or any meetings but want to go on trips etc. They give nothing but want to enjoy the benefits.

Level of participation

- Unclear as to why some patients become active contributors while others are less involved

- Some possible reasons
  1. Anticipated reciprocity
  2. A sense of efficacy
  3. Gain increased recognition and establish a reputation

- 'Uses and gratification' model (Blumler & Katz, 1974)
  - e.g. find information but wish to remain anonymous – lurking
  - e.g. make new friends and connections – take a more active role

Lurking behaviour

- Not everyone will be an active member of an online community
- Number of ‘lurkers’ varies but can be up to 90% of a community
- Lurking = reading but not posting messages (problems with definitions)
- Is lurking a problem?
- Evidence is mixed and limited but lurkers can derive some benefits from simply reading messages but may derive even more benefits if they actively engage. In addition, several studies suggest they are less satisfied with their online community experience

Mo, P.K.H. & Coulson, N.S. (2010). Empowering processes in online support groups among people living with HIV/AIDS: A comparative analysis of ‘lurkers’ and ‘posters’. Computers in Human Behaviour, 26(5), 1183-1193.

What do members talk about?

- A number of studies have examined the content of the communication between members of online support communities

- The main focus of much discussion is on medical and illness topics:
  - Symptoms
  - Diagnoses (including pre and post)
  - Treatments
  - Medications
  - The emotional impact of any aspect of the illness experience

- However, off topic conversation is also common!

How do patients talk online?

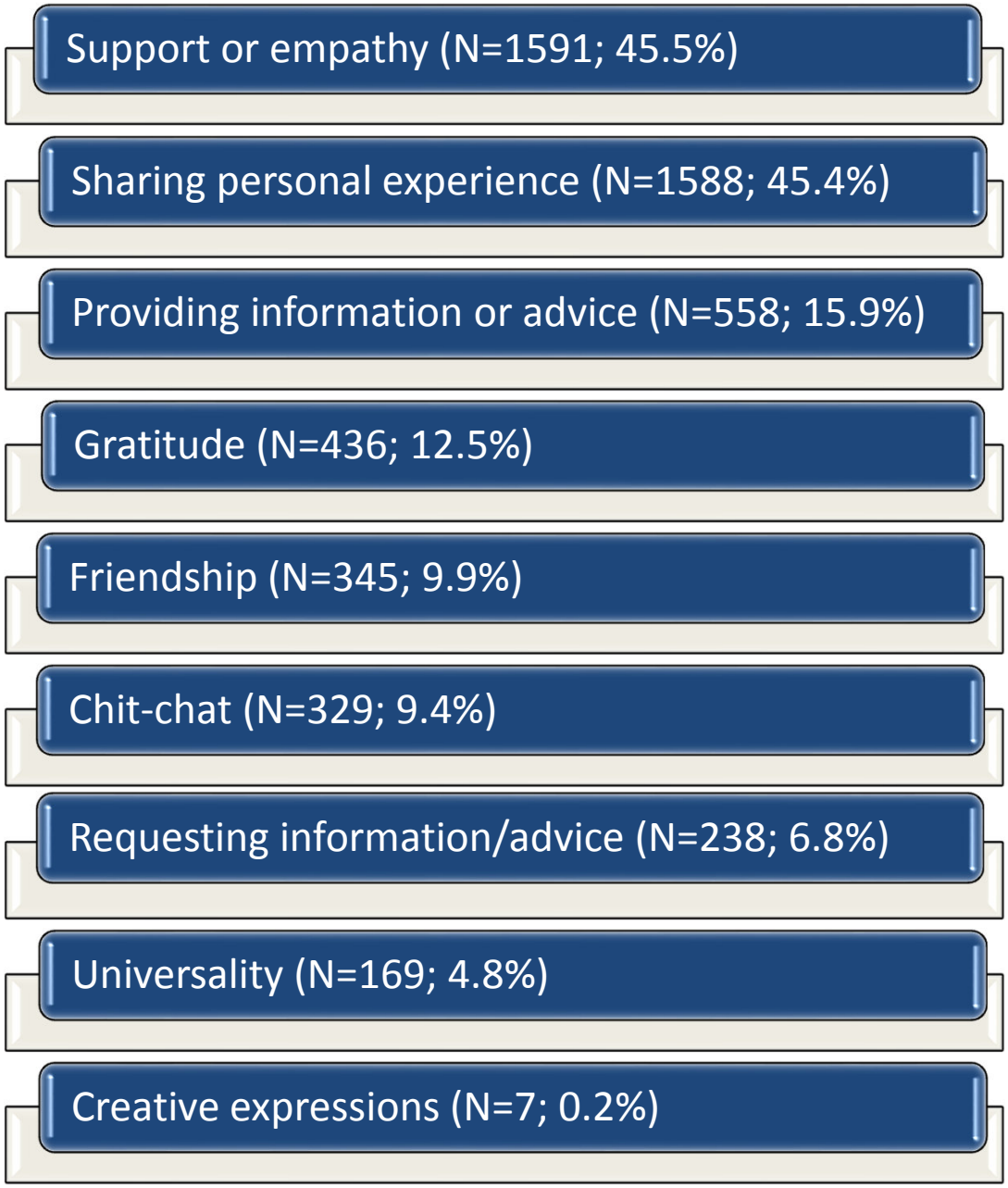
- There has been a considerable body of literature that has analysed the content of the messages posted

- Variety of analytical methods
  - Content
  - Thematic
  - Discourse
  - IPA

Self-help mechanisms

Do online support communities provide similar therapeutic exchanges that occur in face-to-face self-help and peer support groups?

Perron (2002) coined the term 'self-help mechanisms'



Malik, S. & Coulson, N.S. (2010). Examining self-help mechanisms in a web-based infertility support community. *Patient Education & Counseling*, 81(2), 315-318.

Finding

Peer Support Among Individuals with Severe Mental Illness

1. Validation of their approaches to problems increase their confidence and establish **a sense of normalcy** for themselves.
2. **Comparing** one another to each other is considered to provide other peers with an incentive to change for the better either through upward comparison or downward comparison.
3. Those helping each other feel greater interpersonal **competence** from changing other's lives for the better.

Davidson, Chinman, Kloos, Weingarten, Stayner, Kraemer (1999)

Finding	Area	Authors	Year
experienced significantly greater (1) increases in the size of their support network, (2) **increases in their knowledge of community resources,** (3) improvement in their interpersonal skills and ability to deal with the problems of caregiving, (4) **improvement in their relationships with their care receivers**, and (5) decreases in pressing psychological problems.	Carers for the elderly	**Toseland, Rossiter and Labrecque**	1989
Personal empowerment is a form of social capital derived from engagement in the social relations within the **self-help group** that allows members to obtain benefits such as increasing their life satisfaction.	Hong Kong self-help groups	Chung, Mok and Chung	2005

Finding	Area	Authors	Year
can lead to effective coping skills, improved **self**-esteem and personal growth, and collective mobilization for social change and service innovation.	General review	Hasenfeld and Gidron	1993
Members reported personal gains of empathy, emotional information, experiential knowledge and practical information, based on a core value of reciprocity through peer support	carers	Munn-Giddings and McVicar	2006
Learning as an empowerment process: consciousness-raising, acquisition of objective knowledge, learning from others' experiences and discovery of new perspectives in life and in oneself.	women recovering from breast cancer	Stang and Mittelmark	2008
Major facilitator of activism-involvement in improving the medical system	parents of children with cancer	Chesney and Chesler	1993

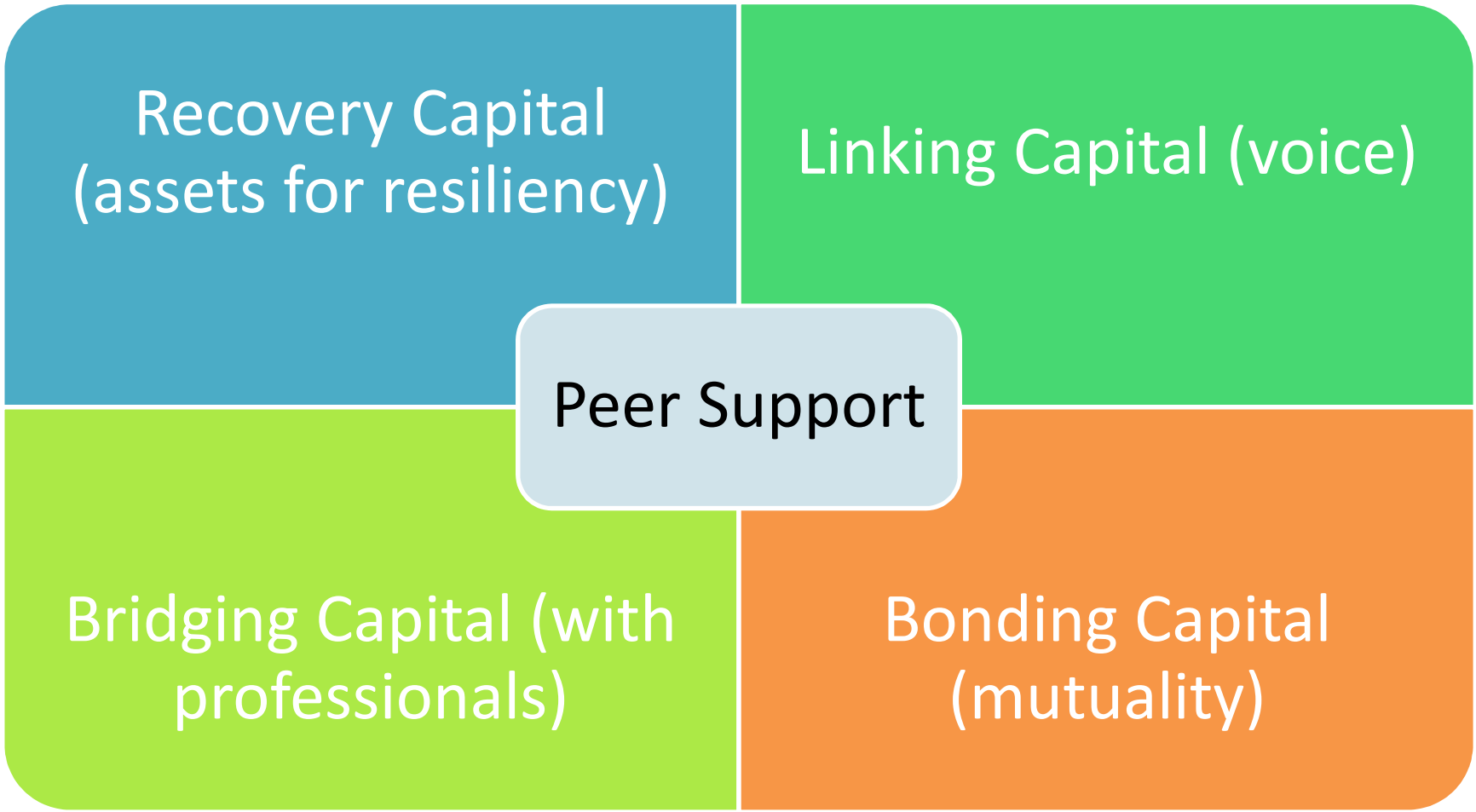
Social Support

Category	N	%
Information	**730**	**56.2**
Advice	538	41.4
Referral to experts	279	21.5
Situation appraisal	103	7.9
Teaching	253	19.5
Esteem	**310**	**23.9**
Compliment	115	8.9
Validation	203	15.6
Relief of blame	38	2.9
Network	**592**	**45.6**
Access	524	40.3
Presence	153	11.8
Companionship	60	4.6

Category	N	%
Emotional	**669**	**51.5**
Relationship	51	3.9
Virtual affection	30	2.3
Confidentiality	92	7.1
Sympathy	117	9.0
Understanding	340	26.2
Encouragement	392	30.2
Prayer	187	14.4
Tangible assistance	**284**	**21.9**
Loan	0	0
Perform direct task	85	6.5
Perform indirect task	0	0
Active participation	48	3.7
Express willingness	192	14.8

Coulson, N.S., Buchanan, H. & Aubeeluck, A. (2007). Social support in cyberspace: A content analysis of communication within a Huntington's disease online support group. *Patient Education & Counseling*, 68(2), 173-178.

Social Impact



Psychosocial benefits of participation?

- To date, there has been a lack of outcome research
- Eysenbach et al., (2004) concluded “lack of robust evidence for the psychological and health benefits of peer-to-peer online communities”
- Very few RCTs BUT are other types of design that has suggested a positive impact
- Cross-sectional surveys, qualitative interviews, case studies and so on

Randomised controlled trial: Example of depression

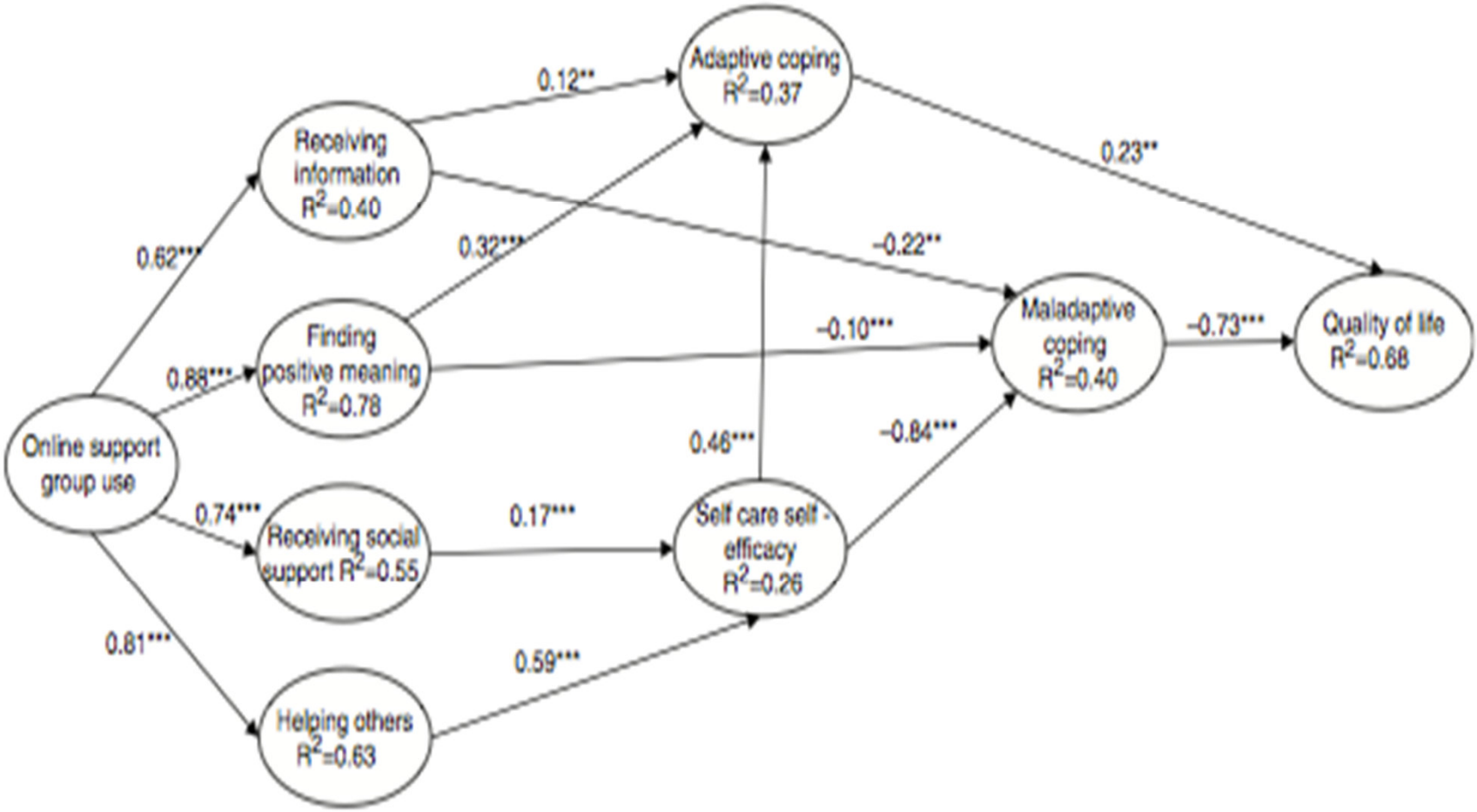
- Griffiths et al., (2012)

- Volunteers with elevated psychological distress (N = 311; 16 to 65 years) were identified using a community based screening postal survey

- 1) Online support group
- 2) Automated depression training programme
- 3) 1 + 2
- 4) control website with delayed access to e-couch

- No benefit at 3 months but greater reduction in depressive symptoms at 6 and 12 months for 1 + 3

Griffiths, K.M., Mackinnon, A.J., Crisp, D.A., Bennett, K. & Farrer, L. (2012). The effectiveness of an online support group for members of the community with depression: A randomised controlled trial. PLOS One, 7(12), 1-9.



Mo, P.K.H. & Coulson, N.S. (2012). Developing a model for online support group use, empowering processes and psychosocial outcomes for individuals living with HIV/AIDS. *Psychology & Health*, 27(4), 445-459.

“**All models are wrong, but some** are **useful**”

(George Box, 1979)

“**There’s nothing so practical as a good theory**”

(Kurt Lewin, 1951)

Why Peer Support Works: Solomon's 5 theoretical frameworks

1. **Social support**: Having a community of people to give physical and emotional comfort, people who love and care, is a moderating factor in the development of psychological and physical disease.
2. **Experiential knowledge**: Members obtain specialized information and perspectives that other members have obtained through living with severe mental illness. Validation of their approaches to problems increases their confidence.

Solomon, Phyllis (2004). "Peer support/peer provided services underlying processes, benefits, and critical ingredients". Psychiatric rehabilitation journal **27** (4): 392–401.

Why Peer Support Works: Solomon's 5 theoretical frameworks

3. **Social learning theory:** Members with experience become creditable role models.
4. **Social comparison theory**: Individuals with similar mental illness are attracted to each other in order to establish a sense of normalcy for themselves. Comparing one another to each other is considered to provide other peers with an incentive to change for the better either through upward comparison or downward comparison

Solomon, Phyllis (2004). "Peer support/peer provided services underlying processes, benefits, and critical ingredients". Psychiatric rehabilitation journal **27** (4): 392–401.

Why Peer Support Works: Solomon's 5 theoretical frameworks

5. **Helper-Therapy Principle**: Riessman (1965) attempted to explain the therapeutic effect for both people in a "helper" and "helpee" relationship within groups: In the process of helping another member, the helper gains an increased sense of self-efficacy making the relationship *mutually beneficial.*

Those helping each other feel greater interpersonal competence from changing other's lives for the better.
The helpers feel they have gained as much as they have given to others.
The helpers receive "personalized learning" from working with helpers.
The helpers' self-esteem improves with the social approval received from those they have helped, putting them at a more advantageous position to help others

Solomon, Phyllis (2004). "Peer support/peer provided services underlying processes, benefits, and critical ingredients". Psychiatric rehabilitation journal **27** (4): 392–401.

SOCIAL COMPARISON

An active ingredient within online support communities

Part 2

THE DOWNSIDE OF ONLINE SUPPORT COMMUNITIES

What negative processes or outcomes concern you?

Discussion

Disadvantages

The research literature has shown more variability in terms of the potential disadvantages

Here are some of the more common issues the early literature suggested were problematic

Misinformation?

- Concern about the accuracy and quality of information exchanged between community members?
  - Health professionals?
  - Patients?

- What does the evidence tell us?
  - Example: van Uden-Kraan et al., (2008)
  - Example: Esquivel (2006)

- Other research? How we explore this question? Methods?

Van Uden-Kraan et al., (2008). Coping with somatic illness in online support groups: Do the feared disadvantages actually occur? Computers in Human Behavior, 24, 309-324.
Esquivel, A., Meric-Bernstam, F. & Bernstam, E. (2006). Accuracy and self correction of information received from an internet breast cancer list: content analysis. BMJ, 332(7547), 939-942

Delayed feedback?

- Many online support communities use an asynchronous format
- TIME may be critical – given that people need support
- How much of a problem?
  - Example: Coulson (2013)
- Extent of the problem?

Addictive?

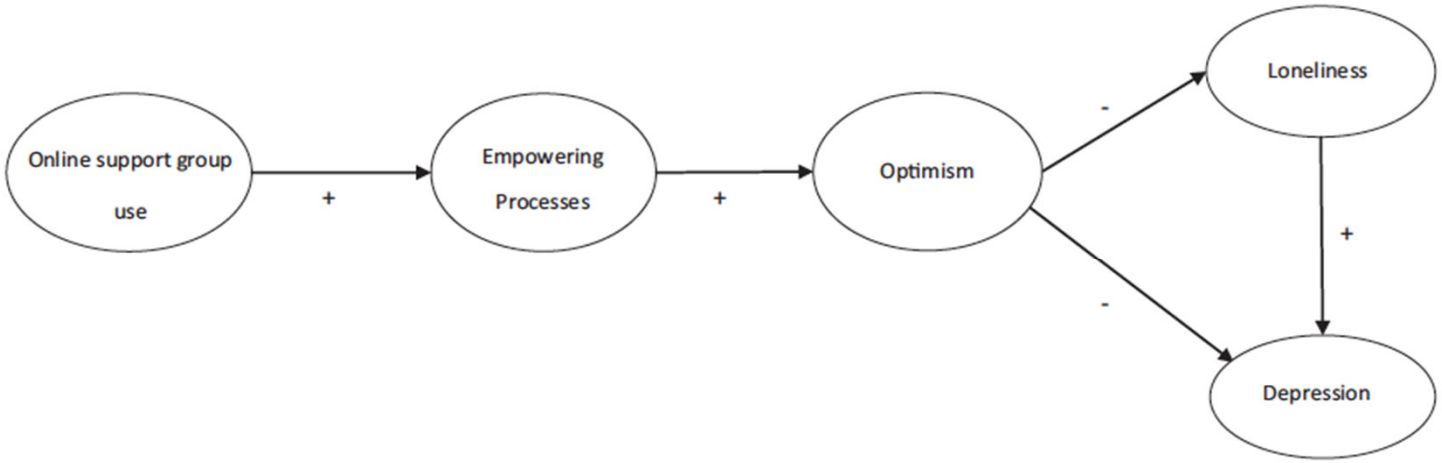
- Early work did suggest that some people may become addicted to the Internet and spend too much time online

- Within the context of online support communities – some members do report spending a lot of time online BUT is this addiction?

Increases social isolation

- Early work which looked at the Internet and impact on people's live did suggest that there may indeed be a problem!

- However – since then many studies have described the impact of participation in online support communities in terms of 'feeling connected', 'no longer alone' or reduced 'loneliness'
  - Example: Mo & Coulson (2014) HIV/AIDS



+ Hypothesized positive relationship between variables
- Hypothesized negative relationship between variables

De-individuation?

- State of lowered self-awareness where an person loses their individual sense of identity and becomes immersed into the identity of a larger group

- Some argue that this deindividuation will be characterised by disinhibited communication such as aggressive behaviour or hostile exchanges (i.e. flaming)

- Absence of non-verbal cues – does this compound the problem?

Infertility

Objective: To explore perceived disadvantages of infertility online support

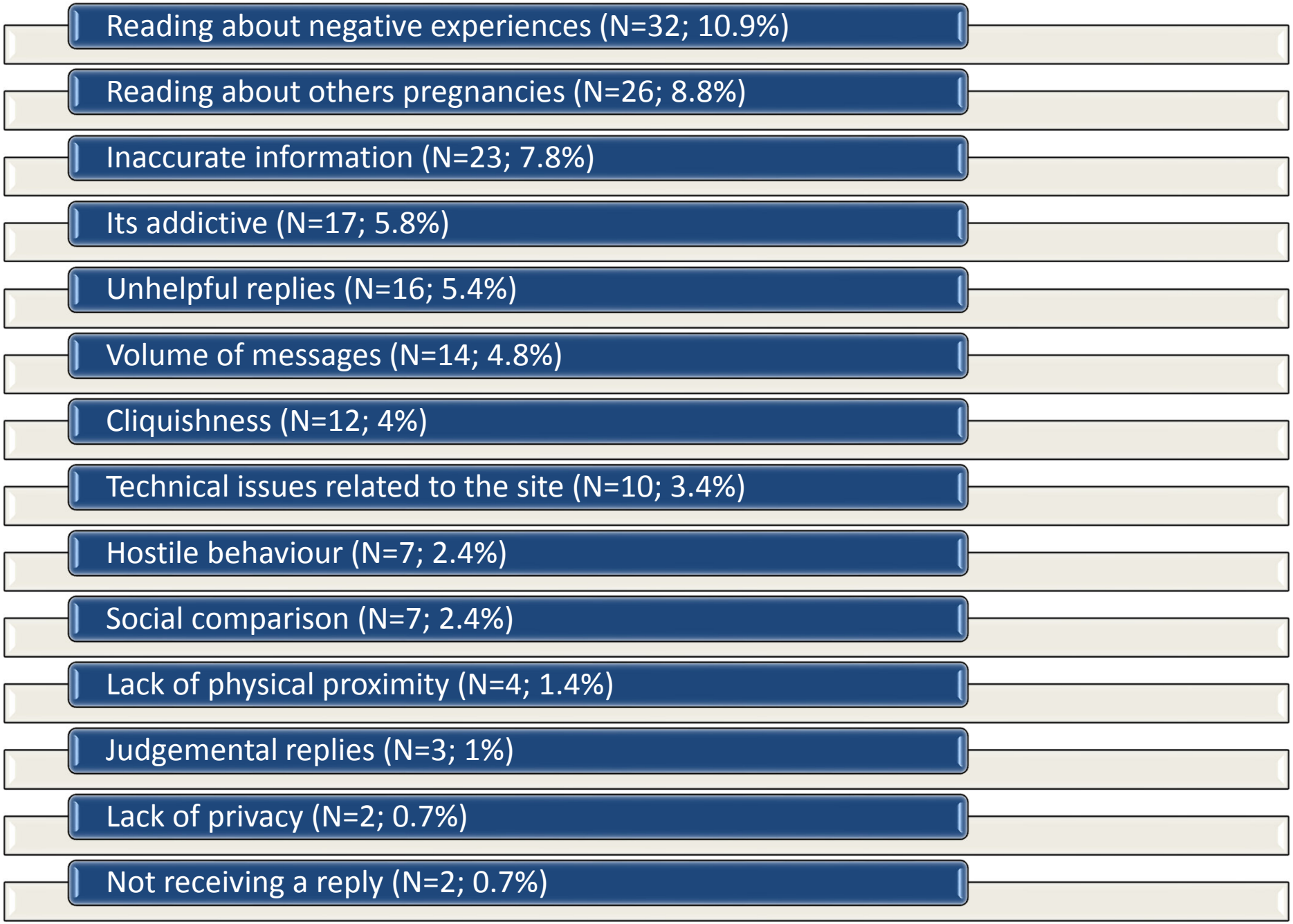
Design: An online survey

Setting: 5 infertility online communities

Participants: 295 patients living with female or male factor infertility, with nearly all female (99.7%) and from the UK (89.4%)

- Did anyone experience any disadvantages and if so, what were they?
  - 170 (57.8%) reported experiencing disadvantages to infertility online support communities
  - 14 different problems were identified
  - Longitudinal research needed to explore the impact of these concerns

Malik, S. & Coulson, N.S. (2010). "*They all supported me but I felt like I suddenly didn't belong anymore*": An exploration of perceived disadvantages to online support seeking. *Journal of Psychosomatic Obstetrics & Gynecology*, 31(3), 140-149.


Reading about negative experiences (N=32; 10.9%)
Reading about others pregnancies (N=26; 8.8%)
Inaccurate information (N=23; 7.8%)
Its addictive (N=17; 5.8%)
Unhelpful replies (N=16; 5.4%)
Volume of messages (N=14; 4.8%)
Cliquishness (N=12; 4%)
Technical issues related to the site (N=10; 3.4%)
Hostile behaviour (N=7; 2.4%)
Social comparison (N=7; 2.4%)
Lack of physical proximity (N=4; 1.4%)
Judgemental replies (N=3; 1%)
Lack of privacy (N=2; 0.7%)
Not receiving a reply (N=2; 0.7%)

Negative Experiences

Objective: To explore how participation in an online support community may impact upon the experience of inflammatory bowel disease (IBD).

Design: An online survey

Setting: 35 IBD online communities

Participants: 249 males and females aged 16–69 years, living with either Crohn's disease (65.9%) or ulcerative colitis (26.1%) or awaiting formal diagnosis (8%)

"Can cause you to panic about what could happen. You can read too much into the symptoms that other Crohn's patients suffer and worry this could happen to you."

"There are a lot of horror stories as mainly really sick people are online (too sick to be elsewhere). People who recover or are in remission stop posting. So we lose access to people who could add immense value by sharing how they recovered."

Coulson, N.S. (2013). How do online patient support communities affect the experience of Inflammatory Bowel disease? An online survey. *Journal of the Royal Society of Medicine Short Reports*, 4, 1-8.

SOCIAL COMPARISON

An active ingredient within online support communities BUT THIS CAN BE BOTH GOOD AND BAD

Part 3

THE IMPORTANCE OF MODERATION / FACILITATION

Skills and Characteristics needed for Managing Online Forums - O'Keefe (2008)

- Open to new ideas and committed to hard work
  - Patience
  - People Skills
  - Clear communication
  - Accessible
  - Participant?
  - Care
  - Able to make hard choices

- Don't have to
  - Know everything
  - Be a technical whizz

Skills and Characteristics needed for Managing Online Forums - O'Keefe (2008)

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  - Participant?
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  - Know everything
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The Process of Moderation - O'Keefe (2008)

- Chain of Command: Administrator > Moderator > Guide > User
  - Decreasing power, scope for promotion
- Steps
  1. Recognising Violations
  2. Removing Violations
  3. Documenting Violations and the Action Taken
  4. Contacting Users
- Typical Violations
  - Outlawed Topics
  - Copyright Infringment
  - Cross-posting
  - Hotlinking
  - Inappropriate / Inflammatory / Vulgar
  - General Breach of Guidlenes

The importance of moderators

What can be learnt from moderators?

Coulson, N.S. & Shaw, R.L. (2013). Nurturing health-related online support groups: Exploring the experiences of patient moderators. *Computers in Human Behaviour*, 29(4), 1695-1701.

Procedure

- Individual invitations sent to online support communities
  - Included a link to the website (surveymonkey)

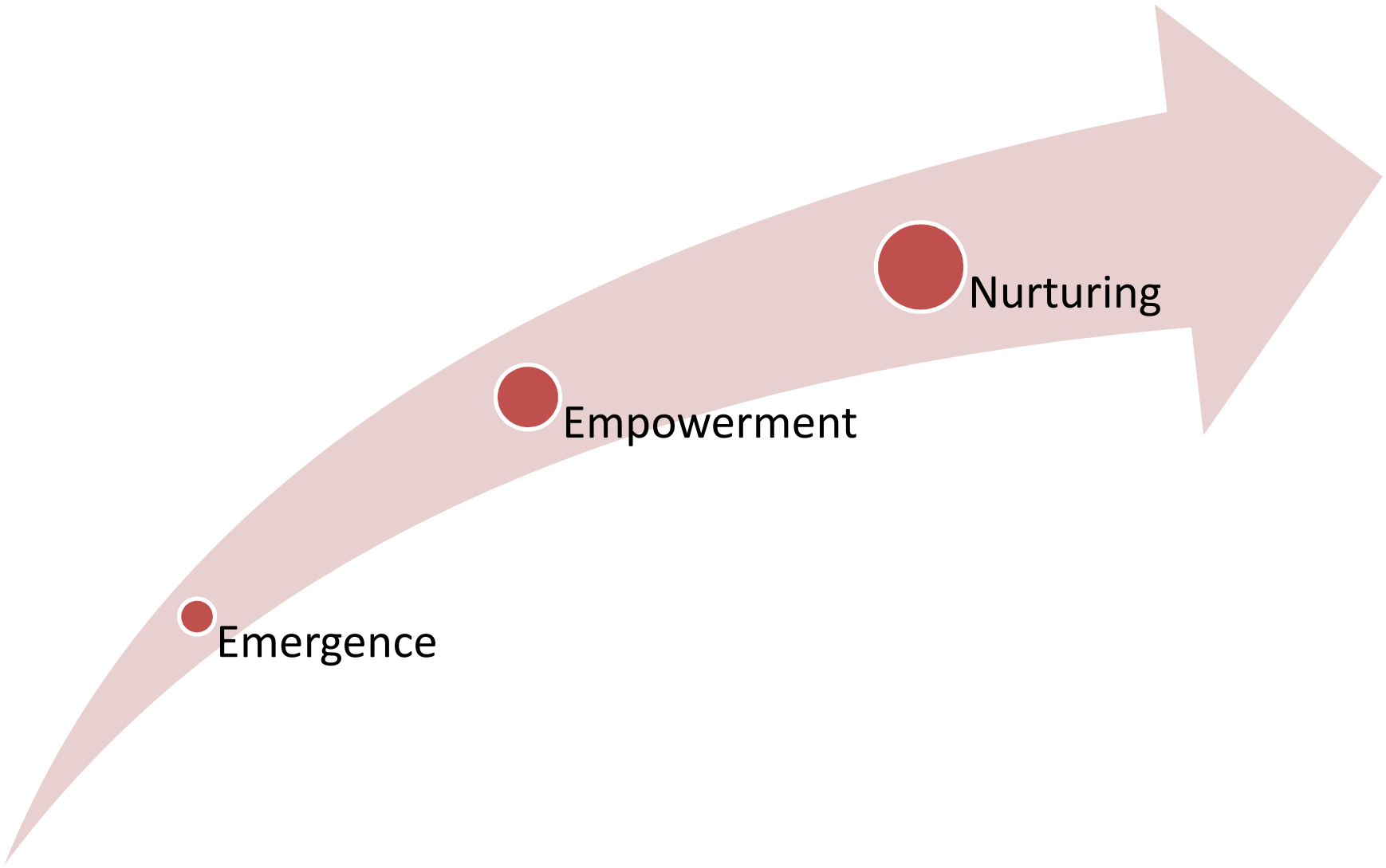
- Online group interview
  - Background to the study, rights as research participants
  - Informed consent
  - A range of questions about their moderator role and experiences: no. of members, length of service, moderator of any other groups, registration details, did they create the group (N=11 said yes), other moderators
  - Open-ended questions: personal benefits, negative aspects, what makes a successful group, any advice for others

Participant characteristics

- 33 online support group moderators participated
  - 25 females/6 males (2 chose not to disclose)
  - Ages ranged from 20 to 70 years (Mean = 48.8)
  - Length of service 1 to 14 years (Mean = 6.27)
  - 19 had not previously or not currently moderating another health-related online support group

- Details about the groups
  - Size ranged from 4 to 33,000 members
  - 24 groups (since some had multiple moderators)
  - Broad range: diabetes, mouth cancer, thyroid disorders, neuromuscular disorders, Down's syndrome, breast cancer, obsessive compulsive disorder, sexual assault and arthritis

Life cycle & moderators' perspectives



Emergence

- This theme reveals reasons cited for setting up the group. A simple reason for setting up a group was a felt need for it because no existing forum catered for people with a particular condition:

  "*Because at the time there just weren't any good support groups on line for those with Thyroid disorders. I had found help myself on line and chose to help others*" (P2)

- Others initiated the forums to help educate people living with sometimes rare conditions, for example P6 described setting up an online forum to enable people to connect with each other between face-to face support meetings. A primary goal was to educate patients about treatments:

"The online support community was founded originally to provide opportunities for members of an in person support group to be in contact between meetings. We received many queries from others who were not participants in our original group, and decided to open the forum to anyone living with uveitis who wished to participate. Our primary mission was to educate patients about ''modern'' treatments for this rare disease, and to provide opportunities for mutual support" (P6)

- Connecting with others experiencing the same condition and feeling validated by them is something moderators felt was important in the emerging identity of the online community:

"Support first and foremost...and the knowledge that they are not the only ones out there with similar problems. A lot of people do not like face to face support" (P24)

- In fact, sharing experiences and caring for others represented strong drivers for the emergence of online forums and created a space where people living with the same condition could interact. Moderators' responses to a question about what members gain from participating also revealed that this feature was central to the ethos of the group:

  "*I decided to set up an online support group so that survivors could support each other*" (P9)

- This theme has shown largely altruistic reasons for setting up the online forums. Having been a patient in need of information and support themselves, many of these moderators set up forums to provide links and circulate valuable health information to individuals who otherwise may have been isolated and ignorant of treatment options. They also created a communal space for user interaction and peer support.

Empowerment

- Here we describe the functions of the group from the moderators' perspectives but also gain insight into what moderators believe patients might gain from participation in the forum.

- Several moderators mentioned experiencing learning and growth through helping others:

  "*Being a moderator has helped me a great deal with my own healing. It has allowed me to turn a horrible experience into something positive*" (P18)

- Acting as moderator constituted ‘helper-therapy’ for some which afforded them a sense of gratitude for being able to give something back and offer others the benefit of their experience:

  “*This group helped me tremendously when I was diagnosed and I wanted to give something back. I am a web designer, so the moderation duties fit well with my skills*” (P7)

- There is a clear link here to **emergence** above; the moderators’ motivation for setting up or becoming involved in the management of forums fosters their own sense of empowerment.

- Having dealt with their own diagnosis as a patient and learned from it these moderators describe the value in being able to support others.

- Engaging regularly with the online group enabled moderators to learn more about their condition, to access a ‘‘*communal brain*’’. This sense of the online forum as a resource hub is further illustrated by moderators’ perception of it as an aid to help patients make treatment decisions along the care pathway.

- Some described the forum as boosting members’ confidence to communicate effectively with health care professionals while others saw it as a gatekeeper to accessing services of which patients may not have been otherwise aware:

  “*Welcome all newcomers and give advice openly – real advice rather than trying to couch answers in medical ‘‘speak’’ that confuses people new to the disease. [..] Give real advice and give out net addresses where they can also get more information. Don’t be afraid to give out advice that could be useful while advising members to discuss everything with their doctors and also to do research on their own*” (P4)

- P4's account shows that moderators need to be careful to convey a balanced approach between using their own experience to give advice and ensuring that members retain connections with the health services.

- The importance of accessing ''traditional'' sources of support provided by health care professionals also became apparent through P8's concerns that some members may depend too much on the group and instead of using it to help take responsibility for managing their condition depended on it in a passive way:

  "*People don't understand what they read, they are intellectually lazy and want everything spoon fed to them. Far too many of the members complain about their chronic pain but when we show them that exercise, gait-training and massage work better than analgesics, they become angry. There is a profound sense of helplessness that pervades the group. [..] It's almost as if most of the members resent the fact that they can help themselves. They appear to want external solutions*" (P8)

- The experience of this moderator has led to disillusionment with the group's disengagement with health care services and self-management advice.

- Members are described as ''*lazy*'' and preferring a ''*quick fix*'' pill rather than making an effort to engage in constructive activities.

- There is a tension here between the forum being perceived as a supportive community which acts as a springboard for further learning and it becoming a crutch for people unable or unwilling to be proactive in self-managing their condition.

- While for most moderators the online forums offer a means of empowerment, there is a need to be cautious that they do not prevent patients from engaging with traditional, local health services.

Nurturance

- In the final theme we discover what is required to nurture the forum and ensure it functions in an appropriate manner. Moderators were asked about their technical abilities to set up the forum initially.

- Several mentioned they benefited from free, open-access platforms, e.g. AOL, Yahoo, Google, and some forums were developed in association with existing websites. Some were novices (‘‘*internet stupid*’’ P6) while others described themselves as ‘‘*internet savvy*’’ (P9).

- Once up and running our participants described soon learning that being a moderator took time.

- There was also a clear message that moderators need to set up boundaries in terms of determining what they are willing to give to the site in the context of (sometimes) their own daily experience as a patient:

"*There are times I feel this is not helping me move through stages I need to move through to live with this disease, yet not be so involved with it that it takes so much of my mental ability and time that I could be spending getting on with thing [sic] not involved with this bone disease. Personal growth for the owner/moderators need to be kept in mind*" (P1)

- Arguably it is the moderator's own responsibility to set ground rules to protect their own well-being but P1's experience demonstrates how easy it can become overwhelming.

- Indeed, these moderators advise others to actively engage in ''*self-care*'' (P22) and argued it was imperative that they develop an emotional resilience:

"*Be prepared to take some heat on the tough calls. Members don't like being told they can't do something. Don't take insults personally*" (P18)

- Part of the ‘‘*armour*’’ these moderators wear comes in the form of establishing clear rules of engagement and enforcing them.

- Dealing with ‘‘*spam*’’ (P10) and being able to spot ‘‘trolls’’ (P23) are early lessons. One participant said moderating was ‘‘*like being a parent, you have to watch for someone breaking the rules*’’ (26) and others gave the impression that dealing with ‘‘*nasty emails*’’ (P23) was commonplace.

- A very clear message portrayed by these moderators was that they wanted to create a safe space for their members and that they were careful to nurture their group in order to protect this feeling of safety.

- To achieve this, moderators described a number of factors which must be in place, many of which come under the jurisdiction of the moderator to maintain:

“*Trust, confidentiality, fairness and courtesy. Many of newest members are scared and confused. They need to feel safe in asking questions without being judged or criticized*” (P7)

- Moderators also described their nurturing role through their ability to ‘‘*listen and give support and love*’’ (P6) and offer ‘‘*compassion, organisation and patience*’’ (P19).

- From these accounts it seems that creating a safe environment for members demands a balance between the characteristics listed above and clear guidance on appropriate conduct

Perspective Taking

The ability to imagine a situation from another person's point of view

Widely regarded as a critical skill for managing interpersonal conflict and fostering positive social relationships

Galinsky, Ku, & Wang (2005) Perspective-taking and self-other overlap: Fostering social bonds and facilitating social coordination in Group Processes and Intergroup Relations, 8, 109-124

- Kindness is a salient theme among these moderators' views about what is important in creating and managing a healthy online forum.

- This relates back to the first theme where we saw moderators setting up online groups through a desire to help others by sharing experiences and caring for them.

- The second theme showed us that moderators too gain from this experience and as many of them are patients themselves, it seems that whether a moderator or a member be, online forums for health conditions, when managed effectively, are a source for patient empowerment.

Practical implications

- How do we work with support community moderators?
- What needs do they have?
- What training should be offered?
- What resources are needed?
- How do we moderate online support communities?