Title.

A thematic analysis of messages posted by moderators within health-related asynchronous online support forums.

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Abstract

Objective: To identify and describe the activities performed by online support community moderators.

Methods: A total of 790 messages were downloaded for analysis. Messages were written by 59 moderators from 6 forums that represent a diverse range of conditions (arthritis, complex regional pain syndrome, Crohn's disease, depression, diabetes and Huntington's disease).

Results: Thematic analysis revealed four themes: *supportive tasks* involve providing help to members, *moderators sharing experiences* shows how they use forums to fulfil their own personal support needs, *making announcements* about new discoveries and upcoming events, and *administrative tasks* such as enforcing rules and deleting spam.

Conclusion: These results are consistent with the helper-therapy principle and provide a new insight into the diverse and varied range of activities carried out by moderators.

Practice implications: Moderators perform many roles, including using forums for their own support needs.

1. Introduction

Online support communities (OSCs) are used to discuss health-related issues with like-minded individuals on the Internet [1], and can play an important role in the self-care and self-management of long-term health conditions [2-4].

Researchers have examined many aspects of OSCs including the socio-demographic and medical profile of members [5, 6], how new members introduce themselves [7, 8], the benefits and disadvantages of engagement [2, 9], what kind of social support individuals exchange [10, 11], and empowering processes that can arise from using them [9, 12].

To date, the majority of research has focused on the individuals who use OSCs. There has been comparatively little research investigating the motivations, activities and experiences of OSC moderators.

1.1. The role of moderators

OSCs are typically run by moderators. The word 'moderator' is difficult to define because the role of the moderator and the activities they perform can vary depending upon the nature of the community [13]. A moderator could be the individual who created that community, a paid member of staff, an unpaid volunteer, a healthcare professional, and/or an individual living with that health condition. Little is known about the activities performed by moderators but it is thought they might potentially welcome new members, stimulate discussions, resolve disagreements, provide specialist knowledge, enforce rules, delete inappropriate messages, and remove inactive discussion threads [14].

Coulson and Shaw [15] surveyed OSC moderators to learn more about their motivations and experiences. They found that moderators often have altruistic reasons for creating an OSC, being a moderator had an empowering effect on the individual, and moderators saw themselves as having a nurturing influence on the OSC. This is consistent with the helper-therapy principle [16], indicating that moderators may derive personal benefits from running OSCs and helping members: they may gain a more realistic perspective on their health condition, feel less dependent on others, and feel socially valued because they have something to offer [17, 18].

Close relationships can develop between moderators and members [19], but there has been a lack of research into the day-to-day experiences and challenges associated with being a moderator. In particular, no studies have examined the activities performed by moderators as evidenced through their online messages.

1.2. Aims

The aim of this study was to identify and describe the current activities performed by OSC moderators.

2. Methods

2.1. Data collection

OSCs can be based on several social media platforms including social networking sites, chat rooms, email lists and discussion forums. Social networking sites such as Facebook typically focus on relationship building, networking and sharing updates [20], whereas discussion forums are message boards used to ask and answer questions [1]. Most forums are asynchronous and have a hierarchical, tree-like structure. A forum can contain several distinct boards that are arranged thematically, where

each board will contain many different threads, and each thread will contain one or more messages written by members. Data was collected from discussion forums because these are the most common type of OSC [21].

Forums were identified through a Google search with the keywords 'support', 'forum', 'community' and the names of various physical and mental health conditions. The following criteria were used to determine suitability for our study: 1) the forum needed to be in the public domain, with user-generated content publically visible without requiring registration to view messages; 2) the forum needed to have a large membership and good daily levels of activity (i.e. new messages being posted); 3) each forum needed to provide their moderator usernames and 4) the forum included a search function which allowed all messages posted by a specific username to be retrieved.

Six forums were chosen that represented a diverse range of physical and mental health conditions: arthritis, complex regional pain syndrome (CRPS), Crohn's disease, depression, diabetes and Huntington's disease. Two forums had search restrictions that only provided access to the 15 most recent messages, so the 15 most recent messages posted by each moderator were selected for analysis. A small number of moderators had posted less than 15 messages, so this produced a total of 790 messages.

Each message was copied into a word processor document for offline use [22]. The original formatting and layout of messages were retained including emoticons and other textual features, but signature lines and personally identifying information were discarded to anonymise the dataset.

2.2. Participants

The sample consisted of all 59 moderators from the six forums described in Section 2.1. One forum had a single moderator username shared by four individuals who could be distinguished by the initials at the bottom of their postings, and the other forums had 55 moderators with their own unique usernames.

Demographic information about participants was limited because OSC members often maintain an anonymous online persona [22, 23]. It was possible to determine the gender of most participants from their username and message content (see Table 1). Table 2 shows the likelihood of males and females being diagnosed with each condition.

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<< INSERT TABLE 2 ABOUT HERE >>

2.3. Analysis

Inductive thematic analysis [32] was used to identify recurring patterns within the dataset. Moderator messages were examined in the context of the discussion threads they were posted in, to also investigate how other members responded to those messages. This made it possible to identify what moderators do and how they engage with forums as evidenced by the content of their postings. Each message was read several times to produce a list of themes summarising the data, then deductive content analysis [33, 34] was used to count the number of messages within each theme. If more than one theme was represented in each message, then all themes were counted.

2.4. Ethical considerations

Ethical approval for this study was granted by the University of Nottingham, and the study was conducted in accordance with British Psychological Society guidelines [35]. To protect the anonymity of participants, any potentially identifying information about participants and research sites has been removed. Additionally, all quotes were checked using Google and edited where needed to ensure they cannot be traced back to the original postings [36].

3. Results

3.1. Theme 1: *Supportive tasks*

Moderators were involved in a range of supportive tasks that appeared to provide members with social support, encouragement and a sense of belonging. 526 messages (66.6%) were included in this theme, with 55 moderators (93.2%) posting this type of message.

Welcome messages were often posted to greet new members ("*Hi and welcome to the forum*"). Members were encouraged to provide information about themselves in their profile, to make it easier for others to get to provide the right kind of support ("*I tried to learn more about your [illness] from your profile, but I didn't see anything. Would you mind letting us know more about yourself?*"). Other members often joined in by saying hello and asking questions. Sometimes the original poster (OP) would reply with more information, and sometimes no further messages were posted.

Moderators often provided information, support and advice. These messages frequently discussed the merits of different treatment programmes, provided information about medications, and suggested potential coping strategies. For example, the following quote suggests a technique that may help to reduce pain levels:

> *A study showed people who shout, scream, and show intense anger at their chronic pain actually lower their current pain levels. […] Yell, hit something soft enough so that you're not injured, etc. When you're finished you'll be completely worn out, then check your pain level.*

These messages were typically posted alongside other members who also offered advice, with the OP often asking further questions or thanking members for their help. If a member was confronted by a complicated problem that was beyond the scope of the forum, moderators would urge the individual to seek professional medical help ("*Phone 111 or contact an out of hours GP for advice. If you are on insulin then follow the sick-day rules […]. In any case, drink plenty of no sugar fluids*"). Other members gave similar advice, and the OP later replied with an update on their situation.

Replies posted by moderators emphasised that the individual is not alone in their experiences, enquired about the wellbeing of individual members, and encouraged members to post follow-up messages that will keep everyone updated regarding how they are feeling and what progress they are making towards overcoming their difficulties ("*Please keep us updated on how you are doing. We care about you and need you here, and so does everyone else in your life*"). The OP would often respond saying how much these messages helped them.

Misunderstandings occasionally arose within the forums, where a message posted by either a moderator or member was misinterpreted by another individual. Moderators would respond to complaints by apologising and explaining their actions, as this quote shows:

> *I am very sorry that you misunderstood my words, I was trying to make what you said seem less powerful and stressful and instead I've upset you. […] Please contact me and we can talk or you can tell me to take a hike but know that I had the best of intentions.*

After this message was posted, the discussion continued normally as if nothing had happened.

3.2. Theme 2: *Moderators sharing experiences*

In addition to supporting others, moderators also appeared to use the forums for their own personal support needs. 214 messages (27.1%) were included in this theme, with 40 moderators (67.8%) posting this type of message.

These messages had some similarities to those in the supportive tasks theme, but moderators talked about their own situation rather than that of other members. For example, they would often post updates about their health condition, share how their illness impacts upon their personal life or career, ask about new medications they have been prescribed, or discuss recent medical appointments:

> *My GI appointment was stressful and I had to really argue my case. I have reached a compromise with my GI, who is putting me on [medication]. Hopefully this will blitz my flare and get me back in remission.*

Some forums had discussion threads where members were encouraged to post a word or number describing how they are feeling on that day, with moderators posting their own messages ("*Fed up*"). Moderators also took part in off-topic discussions such as talking about popular television programmes or the weather ("*We've had some snow and it has been bitterly cold [...]. More bad weather due tonight*").

Face-to-face meetings and other social activities were occasionally mentioned. If a forum activity was planned but the moderator was unable to attend, sometimes they would post a message hoping that everyone else has a nice time ("*I hope you have great weather and a fantastic time, and develop friendships that will last forever*").

Within this theme, the replies received by moderators appeared indistinguishable to the replies that other members receive.

3.3. Theme 3: *Making announcements*

Occasionally, moderators made announcements to the group. Theme 1 sometimes involved providing information to a specific member, whereas announcements addressed all members. Announcements could take several forms including science, current affairs, recruitment and forum announcements. 50 messages (6.3%) were included in this theme, with 13 moderators (22.0%) posting this type of message.

Science announcements were used to disseminate new information about a health condition. For example, a moderator might post an announcement about a new journal article that has been published, a new method of treatment, or a newspaper article about the illness: "*A new paper has been published by scientists at [name of biotech firm], who are looking for ways to control chronic neuropathic pain. Their approach involves using viruses to access the body's pain-transmitting neurological processes.*"

Sometimes announcements were made about developments that may become relevant to members in the future. For example, an announcement might inform members about research that eventually may lead to a cure or new forms of treatment: "*Bionic pancreas could help fight diabetes: Science fiction is expected to become reality in a few years when those suffering from diabetes may be able to buy a bionic pancreas*".

Recruitment announcements were sometimes posted by moderators. These informed members when scientists wanted to recruit participants for surveys and other types of research study. Messages typically explained the rationale for the study, who is conducting it, why it is important to take part, and what potential benefits it might produce. Moderators also posted announcements on behalf of local or national media to enquire if any members would like to take part in radio or television broadcasts to talk about their experiences: "*Radio 4's Today programme would like to interview someone who is undergoing PIGD or who has had a child using this method, if anyone can help*".

Current affairs announcements provided information from local, national or international news. These typically covered topics that are potentially important for everybody: "*Patients who don't need to be in hospital add to burden on NHS: MORE than 500 patients were in hospital when they didn't need to be – taking up bed space that could be allocated to others*".

Forum announcements informed members about opportunities to attend face-to-face meetings where they can meet others and take part in activities. Some announcements promoted conferences organised by the forum to provide individuals with the opportunity to meet others and learn more about their health condition. Other events were more socially orientated and involved taking part in leisure activities: "*Please see below for details about our forthcoming river cruise on the Thames*".

Members sometimes replied to announcements saying they looked forward to reading a scientific paper, expressing their opinions on current affairs, or thanking moderators for telling them about changes to the forum. Announcements about upcoming events received fewer replies, with members instead being directed to booking instructions if they wanted to attend.

3.4. Theme 4: *Administrative tasks*

Moderators performed a range of administrative tasks to keep the forums running smoothly and effectively. This included tasks performed on individual messages, tasks performed on whole discussion threads, and other tasks such as responding to research requests and banning specific users. 35 messages (4.4%) were included in this theme, with 17 moderators (28.8%) posting this type of message.

Individual messages sometimes required administrative attention by moderators. Newly joined members periodically received replies from moderators to clarify forum rules, such as needing to have their first few messages vetted by a moderator before being granted full access to the forum ("*All newly joined members need to have their initial posts approved by a moderator*") or having to post a minimum number of messages before being allowed to use the forum's private messaging facility

("*Private messages will be activated after you've posted three times*"). Members sometimes replied to clarify the rules or apologise for breaking them.

Moderators occasionally edited the messages posted by members ("*I'm happy to edit your posts*"), investigated when messages inexplicably disappeared from the forum ("*I will find out the reason for this and get back to you*"), collated messages from other discussions into a new thread ("*Collating messages here from the cinema card thread*"), and directed members to subgroups that might be a more appropriate place to post their message ("*We have a diet subforum dedicated to that*"). Members rarely replied to these messages, with the discussion either continuing uninterrupted or moving to the recommended subforum.

Another task involved responding to any messages that might be hurtful, disrespectful or offensive to other members. This was particularly important to ensure that the forum provides a safe environment for all members, where individuals can feel comfortable to express themselves and talk openly about their thoughts, feelings and experiences: "*You're welcome to express yourself but please don't say hurtful things. […] We all come here for support and to support others. If you are having problems with someone then please address them privately in a pm.*" The OP did not respond but other members replied. Instead of treating the hurtful message as a personal attack, they attempted to understand why the poster felt so unhappy that they posted the hurtful message.

Discussion threads also sometimes required the administrative attention of moderators. Important threads could be made 'sticky' so that they always appeared at the top of the list of discussion topics, and moderators could toggle this 'sticky' status to convert them back into normal threads ("*It is time to 'unstick' this thread*"). Moderators sometimes moved threads to a more appropriate discussion board, or posted a message to "*bump*" them back to the top of the list of current discussions to bring it to the attention of members ("*Moved and bumped*"). Additionally, old threads were sometimes deleted from the forum to keep the forum running smoothly ("*Some older threads and posts are pruned to free up space to help make the message board work better*"). Several members were unhappy about threads being deleted, which stopped them referring back to their previous messages and also meant data was permanently lost that might benefit others in the future. The moderators did not respond to address these concerns.

Other types of administrative task performed by moderators included responding to research requests from individuals who are interested in using the forum to recruit participants for potential studies: "*There is a formal process to go through before [name of organisation] is happy for any research to be undertaken […]. Please contact Head Office on [address] when you will be given the appropriate advice to proceed.*" Several members expressed an interest in this study and the moderators provided further help with the approval process.

Additionally, moderators had to ban users for posting unwanted and unsolicited "*spam*" messages to the forum ("*[username] banned for spamming*"), and would respond to suggestions for how to improve their website so that information is easier to find ("*We have contacted [name] and our IT specialist and they will look at options to improve this*"). Members rarely responded to these messages.

3.5. Gender differences

Table 3 shows the number of messages in each theme according to gender, and Table 4 shows the number of moderators in each theme according to gender. A similar percentage of male moderators and female moderators performed administrative and supportive tasks, a higher percentage of male moderators posted announcements, and a higher percentage of female moderators used the forum for personal support.

<< INSERT TABLE 3 ABOUT HERE >>

<< INSERT TABLE 4 ABOUT HERE >>

4. Discussion and conclusion

4.1. Discussion

The aim of this study was to identify and describe the current activities performed by OSC moderators. Our analysis revealed that moderators are involved in four distinct areas of activity: supportive tasks, using forums for personal support, making announcements, and administrative tasks.

Supportive tasks were performed by 93.2% of moderators, and were the most common type of activity with 66.6% of messages falling into this category. Forums provide access to a range of information, support and advice [9, 37], and these findings indicate that moderators and members both play an active role in the provision of support. Members often replied saying how much they appreciated this support, and how much it helped them. At the present time, little is known about what proportion of forum support is provided by moderators rather than members, and how this may affect the provision of support.

The second most common type of activity was using the forum for personal support, with 67.8% of moderators and 27.1% of messages in this category. Moderators sometimes create forums because they are dissatisfied with existing sources of support [15]. When creating a forum, moderators might tailor it to their own personal support needs in addition to helping others. Alternatively, a moderator

might initially join a forum as a member and later be promoted to moderator status by the owners. It would then be natural for them to continue using the forum for personal support in addition to helping run the site. Both explanations are consistent with the helper-therapy principle [17, 18], showing how moderators obtain personal benefits from helping others.

Making announcements was an important but less common activity performed by moderators, with 22.0% of moderators and 6.3% of messages falling into this category. Members sometimes replied to these announcements, but with social events they usually followed the booking instructions instead of replying. Forum members sometimes express concerns about feeling isolated and finding it difficult to develop face-to-face relationships with other members [2], and some announcements indicate that forums may have potential for developing in-person relationships. We are not aware of any research that has investigated how commonly forum members meet in person, what kind of forums this occurs on, what factors predict this type of in-person engagement, or how it affects their online relationships.

Administrative tasks were carried out by moderators using a combination of both actions and interventions [38]. Actions were used to move, prune or collate messages, delete spam, and ban members from the forum. Interventions were used to respond to research requests or direct members to subgroups that might be more suited to discussions on a particular topic. Enforcing rules involved using both actions and interventions, for example taking action to edit or delete messages and intervening when members post messages that could be perceived as being hurtful or disrespectful. Interactions between moderators and members were overwhelmingly positive apart from when moderators deleted old threads, leading to the permanent loss of data. Previous researchers have noted the importance of administrative tasks to keep forums running smoothly [38-40] but only 28.8% of moderators posted this type of message and it was the least prevalent type of moderator activity, with only 4.4% of messages falling into this category. A possible explanation is that some moderators may perform administrative tasks 'silently' to minimise disruption to the group, for example deleting spam or dealing with other issues without posting a message to confirm this [15].

There was no evidence of gender differences in the supportive tasks and administrative tasks themes, with male and female moderators posting a similar percentage of messages. This is consistent with the helper-therapy principle and a desire to help others [15, 16]. Male moderators posted a higher percentage of announcements than females, while female moderators posted a higher percentage of messages using the forum for personal support. These differences may partly arise from gender-oriented communication styles, with males more information-focused and females more emotion-focused [41], and partly because females may be more likely to use online support [5]. The Crohn's, depression and Huntington's forums had a large number of female moderators, suggesting that females with these conditions are more likely to use forums and/or become moderators.

Whilst our findings yield a unique insight into the daily functions of OSC moderators, there are some limitations. First, little information was obtained about each moderator so the impact of their background characteristics (e.g. age, length of service, current health status) remains unclear. Second, our dataset included asynchronous forum moderators from a small but diverse range of conditions. Future research should examine the activities of moderators on alternative platforms and across a greater array of health conditions. Third, the forums in this study were in the maturity stage of Iriberri and Leroy's OSC lifecycle [42]. Moderator activities in other stages could differ from those described here, so future research is needed to understand how moderator activities evolve over time.

4.2. Conclusion

Until now, little was known about the activities performed by moderators. Moderators are involved in four main areas of activity: supportive tasks, using forums for personal support, making announcements, and administrative tasks. Nearly all moderators performed supportive tasks, which involve providing help, support and encouragement to members. A large number of moderators also used the forum for their own personal support, including discussing their own difficulties and requesting help from others. Some moderators made announcements, which included educating members about new developments and informing them about social activities. Moderators also performed administrative tasks such as moving messages, deleting spam and intervening when problems arise. These activities could vary at different stages within the lifecycle of OSCs.

4.3. Practice implications

Moderators perform many roles within forums, including using forums for their own support needs.

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Table 1: The gender of participants from each forum.

Forum	Male	Female	Unknown	Total
Arthritis	0	1	3	4
Crohn's	3	26	1	30
CRPS	1	2	0	3
Depression	0	6	0	6
Diabetes	3	3	0	6
Huntington's	1	7	2	10
Total	8	45	6	59

Table 2: The likelihood of each gender being diagnosed.

Condition	Gender distribution
Arthritis	Rheumatoid arthritis: Females are 2.5 times more likely to be diagnosed than males [24].
	Osteoarthritis: Females are generally at higher risk than males [25].
Crohn's	Females are slightly more likely to be diagnosed than males [26].
CRPS	Females 4 times more likely to be diagnosed than males [27, 28].
Depression	Females 1.7 times more likely to be diagnosed than males [29].
Diabetes	Males slightly more likely to be diagnosed than females [30].
Huntington's	Males and females equally likely to be diagnosed [31].

Table 3: Number of messages in each theme according to gender

Theme	Male		Female	
	n	%	n	%
Supportive tasks	81	67.5%	415	66.1%
Moderators sharing experiences	21	17.5%	191	30.4%
Making announcements	18	15.0%	30	4.8%
Administrative tasks	3	2.5%	22	3.5%

Table 4: Number of moderators in each theme according to gender

Theme	Male		Female	
	n	%	n	%
Supportive tasks	8	100.0%	44	97.8%
Moderators sharing experiences	5	62.5%	34	75.6%
Making announcements	3	37.5%	9	20.0%
Administrative tasks	2	25.0%	13	28.9%