

Understanding the use of heart failure online health forums: a qualitative study

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Aims

Heart failure is a major public health challenge and is described as an epidemic. Many people resort to the internet as a source of health information and online health forums have become an increasingly common way to obtain information and support regarding health-related issues. This study aims to explore what information people concerned about heart failure seek from online health forums, and how this shapes decision-making, trust, and interactions with healthcare professionals.

Methods and results

Widely available internet search engines (Google, Yahoo, and Bing) were used to identify online health forums, accessed by people seeking information on heart failure. Comments posted between 2016 and 2019 were screened, downloaded, and analysed thematically. Normalization Process Theory provided the underlying conceptual lens to inform analysis. Ten online health forums were identified, and 204 individual posts analysed. Three themes were identified [(information and support needs; online diagnosis; and relationship with healthcare professionals (HCPs)]. The most common purpose for using online health forums was to plug information/knowledge gaps surrounding diagnosis or treatments (e.g. discussion of results, medication/health insurance queries). They were used as a tool to aid decision-making regarding, (i) whether to seek further medical attention and (ii) lifestyle choices, medications, and other advice surrounding concerns. Negative experiences with HCPs were discussed, and sometimes online health forums appeared to promote distrust with HCPs.

Conclusion

Online health forums offer a supportive platform and help fill key informational gaps. However, online forums may amplify distrust with HCPs.

Keywords

Heart failure • Consumer health information • Online health forums • eHealth • Peer-to-peer health-care • Communications media

Implications for practice

- It will be important for nurses and other healthcare professionals to discuss use of online health forums during consultations to ensure a clearer understanding of current patient knowledge and beliefs.
- Nurses and healthcare systems need to consider methods and provide more support and resources to better address the healthcare information needs of people with heart failure.
- Health care systems should consider hosting online health forums to provide support and ensure the information provided is reliable.
- Online health forums may amplify distrust with healthcare professionals, and it will be important to acknowledge this may be an issue that needs addressed within consultations.

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Introduction

A growing number of websites provide a platform for individuals with specific chronic conditions to interact with one another, share experiences and provide emotional support.^{1,2}

Heart failure is a clinical syndrome of symptoms (e.g. breathlessness, fatigue) and signs (e.g. oedema),³ and heart focused online health forums can be used by peers to discuss these symptoms.

Online health forums are frequently used by the public and patients as a health information source as well as a communication channel for people interacting with others experiencing the same symptoms or conditions.⁴⁻⁶ They also have the advantage of not being constrained by temporal and geographical boundaries.⁷ It has been argued that accessing online health information can impact patient/healthcare professional (HCP) relationships,⁸⁻¹⁰

Previous literature has suggested that HCP's should improve their awareness about online health information and forums, so they could recommend reliable resources to their patients.¹¹ Most studies have examined the use of online health forums in general,^{7,12,13} while others have looked at specific conditions such as multiple sclerosis.^{14,15} There is little research that has examined how online health forums influence decision-making or relationships with HCPs. No studies were found which included the observation of information and use of heart failure online health forums.

This article addresses the following research questions:

- What information do people concerned about heart failure seek when using online health forums for self-diagnosis?
- How does this shape their decision-making around self-diagnosis?
- How does the use of online health forums, in the context of heart failure, affect people's trust in HCPs?

Methods

This qualitative descriptive study examined online health forums for those with heart failure or those looking to understand whether their symptoms might suggest a diagnosis of heart failure. We used an inductive version of thematic analysis informed by Braun and Clarke¹⁶ and conceptualized our data through a Normalization Process Theory (NPT) lens.¹⁷ Normalization Process Theory is a useful framework to explain and understand how people implement new interventions into their everyday routines through four constructs: coherence, cognitive participation, collective action, and reflexive monitoring.¹⁷ The theory is primarily concerned with the work people do, interacting with each other and to make sense of processes in order to normalize actions and behaviours.¹⁷ The theoretical lens was used to provide insight into the analysis. With the same data set, we conducted another study analysing the diagnostic accuracy of responses to these posts.¹⁸

Data collection and analysis

Widely used internet search engines (Google, Yahoo, and Bing), were used to identify online health forums that met the pre-defined eligibility criteria outlined in [Table 1](#). The search terms used were 'heart failure online support forums' and 'online health discussion forums for heart failure'.

We collected internet discussion forum conversations that were in the public domain and did not require a login to review the posts.

Text posted between March 2016 and March 2019 was collected from each site for thematic analysis.¹⁶ Usernames were not extracted from the data and identifying information was deleted to protect anonymity of participants; only the content of posts were included. A thematic analysis, informed by Braun and Clarke,¹⁶ was undertaken to establish a list of themes and sub-themes. Three themes were identified from the thematic analysis ([Table 2](#)). Most comments were anonymous and provided few details about the person, most commonly stating their age and gender.

Each item of extracted data was coded independently and then mapped onto the constructs of the NPT framework ([Table 3](#)) to aid conceptualization of the data. Coding clinics were held to ensure the robustness of the coding frames.

Ethics

This study was granted ethics approval from the College of Medicine, Veterinary and Life Sciences ethics committee at the University of Glasgow (200180115) and conforms with the principles outlined in the Declaration of Helsinki.¹⁹ Informed consent was not sought as the data was collected from open access websites already in the public domain.

Results

Screening

The search returned 114 results, but only 10 forums met our eligibility criteria ([Figure 1](#)). From these, 204 specific posts were downloaded and analysed. Four online health forums were identified by Google, six by Yahoo, and Bing did not identify any additional online health forums.

Three major themes (information and support needs, online diagnosis, anxiety/trust issues, and relationship with the HCP) and several subthemes were identified from the analysis ([Table 2](#)).

Gender was specified in 54/204 posts. Of these, 28 were females, and 26 males. Ninety-two posts specified the participants' age (see [Table 4](#)). Most posts were written by the individual themselves ($n = 182$), and others were written for advice about relatives ($n = 22$).

[Table 2](#) provides exemplar quotes relating to the data within each of the themes.

Information and support needs

This theme describes the types of information sought by people from online health forums. This covered several topics: discussion of results; support; the life expectancy of people diagnosed with heart failure; health insurance; medications; lifestyle, diet, and exercise; and symptoms of heart failure. These relate mostly to the NPT theoretical constructs of coherence (sense-making work) and collective action (enacting work). However, some of the issues raised related to cognitive participation (relationship work) when people were seeking advice and supportive information.

Discussion of results

People often failed to adequately understand the results of tests or investigations, sometimes this was attributed to poor communication with HCPs. Frequently, people posted their doctor's summary and sought input from other forum members to determine its meaning. They sought to gain a better understanding from the online health forums. It appeared that people often felt HCPs did not have enough

Table 1 Eligibility criteria

Inclusion	Exclusion
<ul style="list-style-type: none"> • Google, Yahoo, and Bing search engines. • Only the first two result pages of each search engine will be analysed. • Selected forums must be about heart failure. Can be about 'heart diseases', if it includes posts on heart failure. • Discussion posts will only be analysed from the year 2016 to the current year. This year was chosen as the Scottish Intercollegiate Guide Network (SIGN) guidelines for heart failure were last updated in 2016. 	<ul style="list-style-type: none"> • No other search engines other than Google, Yahoo, and Bing, as these were the three most popular search engines. • No pages to be searched further than the first two result pages due to the reported rarity that users would search beyond the second page. • Forums that do not include discussion about heart failure. • No posts will be screened before 2016. • Websites with forums whose purpose of discussion is not health-related will be excluded and if they do not allow input from public/patients and caregivers (for instance expert opinion or professional advice websites online). • Any discussion posts that declare the individual is under the age of 18 will be excluded.

time to adequately explain results; they did not understand the discussion with the HCPs; or the results were to be discussed in a follow-up meeting.

Support

Many people used online health forums to find support. This was particularly true for those who were diagnosed with heart failure and struggled to cope with the impact it had on their lives. Online health forums seemed to help people find a platform to share similar experiences and gain support when talking to other people living with the same condition. This seemed beneficial since some individuals reported finding it difficult to discuss their condition with family and loved ones and the presence of online health forums contributed to them feeling they were not alone.

Heart failure diagnosis and implications for life expectancy

Following a heart failure diagnosis, the life expectancy forecast represented the most frequently asked question. There were examples of people who had not yet been diagnosed but were concerned about future diagnoses and it became evident that this was a popular question to ask online. Usually, people sought this information to prepare themselves for what they may hear from the HCP.

Health insurance

Online health forums were one of the primary options for people who are not covered by health insurance and living in countries where there is not universal access to free healthcare. In these scenarios, individuals searched the internet and self-diagnosed by utilising online health forums to enable them to decide if further medical attention should be sought. Online health forums had the advantage of being free and accessible at any given time and appeared to provide an important source of information for those not covered by health insurance. People also queried if their health insurance would cover the consultations and treatments they needed.

Medications

When already diagnosed with heart failure, individuals sought information on their medication side effects. People shared the symptoms they experienced since starting to take the medication, looking for advice. In addition, people posted questioning the reasoning behind an increase in medications or why dosages may be changed to check the accuracy of the advice they received.

Lifestyle, diet, and exercise

Usually, individuals recently diagnosed with heart failure wanted to learn more about their condition and how it would affect their lifestyle. They related easily with people who received the same diagnosis, when communicating with them. Many posts concerned the necessary lifestyle changes to embrace for preventing heart failure exacerbations.

Symptoms of heart failure

Breathlessness and exhaustion were the most commonly described symptoms of heart failure. Other symptoms included chest pain, heart pounding, palpitations, dizziness, and swollen legs. In most cases, posts involved undiagnosed individuals seeking a diagnosis, or those anxious about heart failure symptoms. In addition, individuals posted that they experienced such symptoms, while awaiting test results.

People found a connection through sharing symptom experiences on online health forums which helped to reduce isolation. In extreme circumstances, some individuals complained that they felt they had to choose between managing their symptoms or possible death.

Online diagnosis

Online health forums were used to guess a diagnosis from peers' experiences, to understand signs and symptoms, to discuss heart failure, to garner support, and to aid decision-making (Figure 2). This section is divided into two sub-themes: self-diagnosing online and internet vs. HCP diagnosis. These issues related to the NPT

Table 2 List of themes, NPT constructs, and participant quotes

Themes	Participant quotes
1. Information and support needs Coherence (CO), collective action (CA), and cognitive participation (CP)	<ul style="list-style-type: none"> a. Discussion of results b. 'I just want to know more about what it means. The visual ejection fraction is estimated at 35–40%. . . The study was technically difficult.' c. Support d. 'I have been diagnosed with heart failure for less than a year. . . Does anyone else feel alone even though you have a partner? . . . In need of support.' e. Heart failure diagnosis and implications for life expectancy f. 'I'm so scared of dying. . . what's the life expectancy like?' g. Health insurance h. 'I'm just worried it's a heart issue. . . No health insurance isn't helping the situation' i. Medications j. 'Why does my Ramipril need to be increased if I'm feeling ok? Don't really know much about this illness and the long-term issues involved, just get handed leaflets.' k. Lifestyle, diet, and exercise l. 'What medications, diet or lifestyle modifications must she do?' m. Symptoms of heart failure n. 'I am tired all the time and very breathless. . . also just had some swelling to my ankles. I am not overweight, also just started to get very heavy legs while walking upstairs. . . I am so worried I have heart failure.'
2. Online diagnosis Coherence (CO) and cognitive participation (CP)	<ul style="list-style-type: none"> a. Self-diagnosing online b. 'I have been googling my symptoms (i.e. Doing just what the doctors seem to hate people doing!) and I seem to have all the symptoms of either heart valve problems or heart failure' c. 'I've been experiencing a cough, occasional palpitations, and sometimes having trouble taking very deep breaths and upon Googling. . . I saw that congestive heart failure was a possibility. . . What are the chances of that?' d. Internet vs. healthcare professional's diagnosis e. 'I don't see the cardiologist until Thursday so of course I Google Impaired Left Ventricular Relaxation and all I see is I have heart disease, but my doctor is acting like it's nothing'.
3. Relationship with HCP's Cognitive participation (CP), collective action (CA), and reflexive monitoring (RM)	<ul style="list-style-type: none"> a. Anxiety/trust b. 'I have health anxiety so I'm terrified I have heart failure'. c. 'My previous cardiologist lied to me at the other hospital and told me I was mild and I shouldn't progress'. d. Time e. 'I have the results and I have asked him to go over them with me. He said he has so many patients that he doesn't have time. . . Is there a site I can find that can tell me what these results mean?' f. Behaviour g. 'My doctor doesn't seem to be in any sort of rush to help me'. h. Communication <p>'My doctor hardly speaks to me so none of my worries have been eased by him at all'.</p>

Table 3 Normalization Process Theory coding frame for people seeking peer-to-peer healthcare advice about heart failure symptoms through online health discussion forums

Coherence (sense-making work)	Cognitive participation (relationship work)	Collective action (enacting work)	Reflexive monitoring (appraisal work)
Differentiation Using online health forums and communities to gain information and self-diagnose.	Initiation The peer-to-peer engagement within the groups and seeking assurance.	Interactional workability Communicating complex health issues and experiences online with peers.	Systemization Determining the benefits and risks of online self-diagnosis and health information seeking on online health forums.
Communal specification Asking follow-up questions to understand the individuals situation/experience, to increase understanding and build a response.	Enrolment Peers reactions and behaviours towards other peers' comments. Communicating effectively to ensure a resolution and minimizing conflict of opinions.	Relational integration The influence of sharing health advice with others and gaining support, and the impact this has on the individual. Maintaining a level of confidence and accountability to continue using the online forums.	Communal appraisal Working together on the internet to determine and evaluate the value of certain treatments. To aid decision-making on treatments.
Individual specification People achieving an understanding of their diagnosis and its implications through health information gained via the internet through peers.	Legitimation Working together in responses to reach a conclusion. Sharing similar experiences to ensure relevance and offer opinions. Justifying concerns and difficulties.	Skillset workability The effect of using online information on roles and responsibilities of members of the public or HCPs. The impact online information has on the decision-making process.	Individual appraisal Collecting information on the internet to determine how effective their treatment is and to help appraise their HCPs advice.
Internalization Peoples understanding of using the internet to self-diagnose and knowing if this is their preference or if they value the role of the HCP consultations instead.	Activation Communicating effectively with peers by expressing relatability and assurance.	Contextual integration Integrating online self-diagnosis and health information into social circumstances.	Reconfiguration Individuals decision-making process of how effective online health forums are for diagnosing and seeking health information for heart failure. The impact this has on relationships with their HCP.

constructs of coherence (sense-making work) and cognitive participation (relationship work).

Self-diagnosing online

People often became concerned about navigating web sources to find online information and misunderstanding it. Many people reported searching the web prior to using the discussion forums. Online health forums were usually used during the second stage of the diagnostic process (after web searching), or by those who had already received a heart failure diagnosis from an HCP when they were seeking clarification about issues. Additionally, they were used if an individual had not yet received a diagnosis or was unhappy with information received from HCPs.

Peer-to-peer diagnosis on online health forums offered a more personalized approach. The peer-to-peer diagnostic process was typically used to diagnose signs and symptoms; awaiting results from tests; concerns for family members; and people who have either been recently diagnosed or already have heart failure to connect with others in similar circumstances and exchange experiences. This allowed a community to develop online. People often reported that

sharing similar experiences via online health forums was helpful and reassuring.

Online health forums contributed to the individuals' decision-making process as they served as a tool to gain information that would inform next steps (Figure 2).

Internet vs. healthcare professional diagnosis

After web searching, people may decide to seek medical attention or be satisfied with the information they gained. However, people sometimes used the internet after a healthcare consultation, and received answers different to the HCP's diagnosis. This led to individuals becoming confused and referring back to online health forums for further guidance (Figure 2).

Relationship with healthcare professionals

This can be subdivided into four subthemes: anxiety, time, behaviour, and communication. Anxiety symptoms can be very similar to the ones displayed in heart conditions and people could often seek advice regarding whether their symptoms were 'in my head or my heart'.

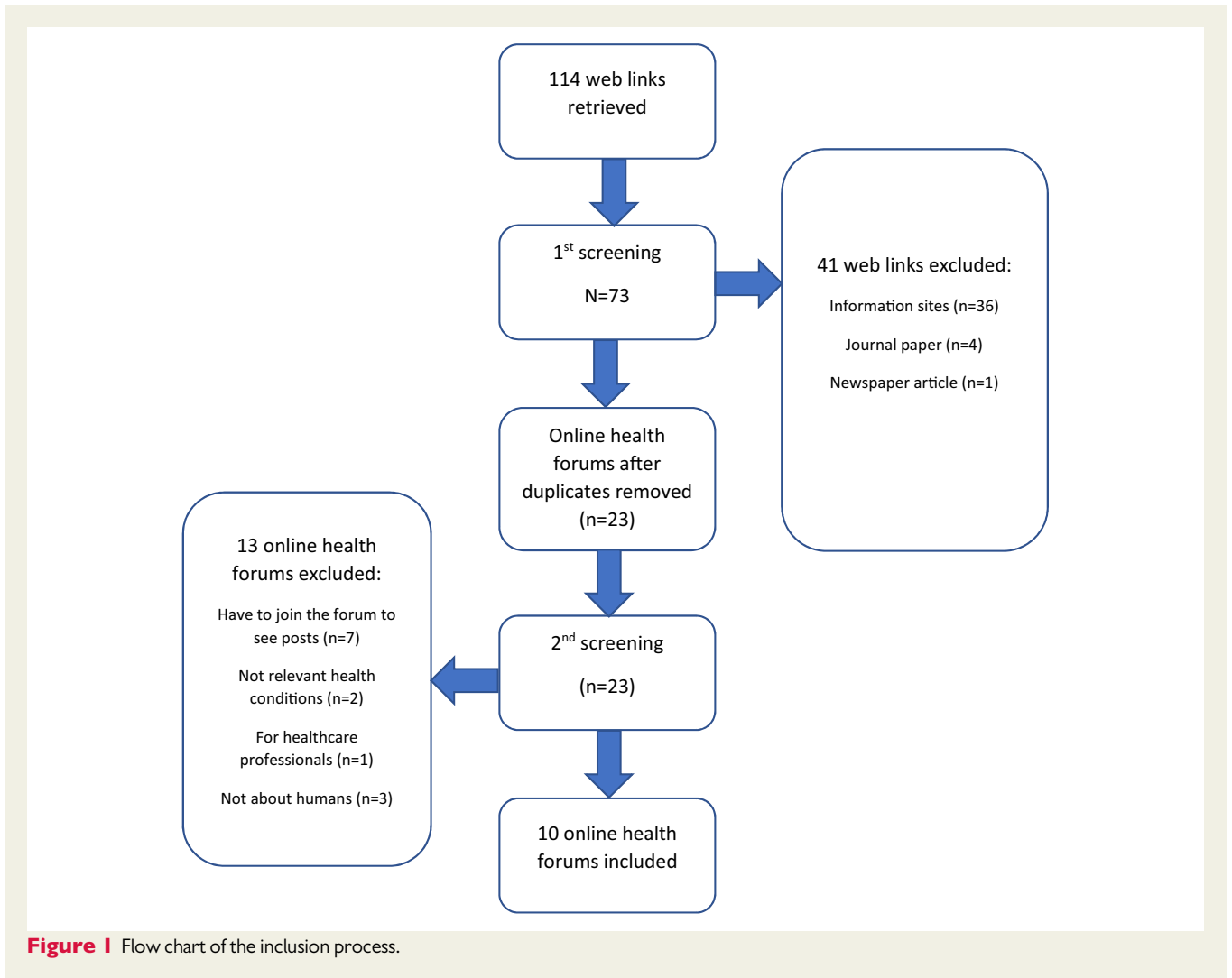


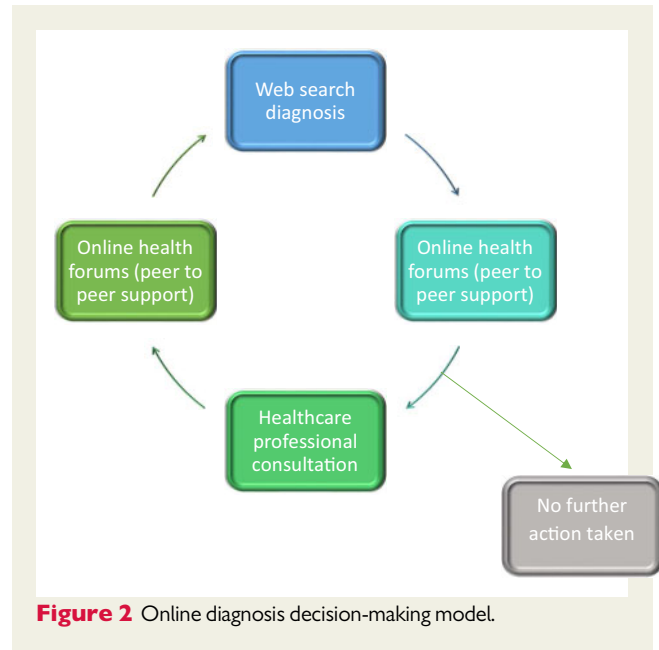
Table 4 Frequency of posts in each age group

Age	No. of posts
18–24	35
25–29	28
30–35	13
36–39	4
40–49	8
>50	4

Others sought advice as they lacked confidence in the HCP. This theme maps onto the cognitive participation (relationship work), collective action (operationalization work), and reflexive monitoring (appraisal) constructs of NPT (Table 3).

Anxiety

Many people posting on online health forums declared that they already had self-diagnosed anxiety but were convinced there was more to what they were experiencing. Interestingly, when they



received a favourable diagnosis from their HCP (they do not have heart failure), this was insufficient to appease them. Individuals could become further distressed, as they felt no one was believing them.

Several posts were from individuals who had consulted with an HCP and received normal test results but still believed they were suffering from heart issues. Some individuals requested repeat tests several times, while others sought a second professional opinion. It was frequently mentioned that people saw multiple doctors due to a lack of trust and because of their persistent scepticism about test results.

Some people, having researched their symptoms and concluded that they have heart failure, perceived that they were being written off and not taken seriously and grew to distrust their HCP.

Time

People often used online health forums when they felt they did not have enough time within the HCP consultation to address all their concerns. They felt there was only enough time for the HCP assessment and not enough for the person receiving the diagnosis to process the information and ask appropriate questions. This was a common reason for using online health forums, to fill information gaps due to the time constraints within the consultation.

Behaviour

Some people perceived that they were not being taken seriously by their HCPs. Individuals sensed that they were becoming an annoyance to the HCPs, who were increasingly impatient with their problems and suspect that their HCP may not believe their problems anymore. People reported that when their HCP responded negatively towards them, it triggered distrust and conflict, which led them to online health forums to seek alternative advice.

Healthcare professional's behaviour towards individuals was shown to have an impact on trust within the relationship. Many people who use online health forums went to this source either due to a lack of trust with their HCP (as described above), or a lack of understanding of the information they were given. As people engaged with other peers, it appeared possible that it could cause further distrust as they heard other users' negative experiences.

Communication

Several posts stated that HCPs were not providing people with the information they desired and communicating with them the way they hoped for, which led them to access the online health forums. Reportedly, HCPs did not explain the results clearly. In addition, others felt unable to talk to their HCP, because they kept receiving an anxiety diagnosis, even though they were certain it was not.

After a heart failure diagnosis, some individuals felt they were not given sufficient information regarding how this would influence their lives. Some felt that their HCPs were vague and, when diagnosed, they sensed that some HCPs were not forthcoming with information about the severity of their condition.

Discussion

Online health forums appear to be an important and valued source of information for those with heart failure/symptoms, who are uninsured and lack access to healthcare, or those seeking to fill

knowledge gaps between consultations. It was also a place people could go to enhance understanding through interaction with others with similar experiences. People had a range of different reasons for using online health forums. While some wanted an opportunity to discuss results, others sought information variously about the life expectancy of patients diagnosed with heart failure, medications, lifestyle, diet, exercise, health insurance queries, and symptoms of heart failure. Online health forums served as a tool to support the decision-making process and to improve understanding of diagnosis, treatment, results, or other information provided by HCPs. The evidence from this study suggests that online health forums may promote distrust in HCPs.

Normalization Process Theory has helped bring focus to the important aspects of the information people concerned about heart failure seek on online health forums and how this shapes decision-making, trust, and interactions with HCPs through information and support needs (coherence—sense-making work; collective action—enacting work; and cognitive participation—relationship work), online diagnosis (coherence—sense-making work and cognitive participation—relationship work), and relationships with HCPs (cognitive participation—relationship work; collective action—enacting work; and reflexive monitoring—appraisal work).

Previous research has examined how online health forums satisfy patients' needs,^{20,21} and our findings resonate with that earlier work in relation to how people use online health forums to gain support and address gaps in understanding and knowledge.²² This tended to be additional information seeking alongside HCP consultations as users felt they had unanswered questions due to lack of time in consultations.⁸ The prominence of peer-to-peer and informational support described here is consistent with previous research.^{2,23} As with previous research¹² we found that discussions centre on medications, lifestyle factors (diet and exercise), and the impact their diagnosis or symptoms could have on their lifestyle.

To our knowledge, this study is the first to report that online health forums could amplify distrust with HCPs. Many people go to online health forums when they are unhappy with their healthcare; feel insufficiently supported; or feel information from HCPs is unclear or inadequate. Online health forums can gather a collection of peers with similar negative experiences which can promote distrust with HCPs. Another novel finding is that lack of insurance coverage forced some people to use online health forums as a decision-making tool. Additionally, many use online health forums to inform decision-making regarding whether they should seek further medical attention, change medication, or to inform lifestyle choices.

Healthcare professional's behaviour, communication strategies, and responses greatly influenced people's decision-making process. If patients felt comfortable and listened to, it would increase their trust. However, if they felt dismissed, judged for using online sources or felt rushed in the appointment, it led to more negative feelings causing distrust and the possibility of changing practitioners and using online health forums.

Online health forums were used to facilitate understanding of medical terms and results, suggesting the use of medical jargon during consultations remains a problem.²⁴ Previous work has suggested online health forums help support people to better understand health information.²⁵ As a health information source, the internet is here to

stay, and it is likely to continue to grow and advance.²⁶ If it is to become an effective and reliable tool supporting healthcare systems, HCPs must learn to work alongside prepared patients, while encouraging dissemination of accurate information.

The seeking of health information from online health forums is well documented and the evidence suggests that users benefit from this information.^{27,28} While previous research has predominately focused on the supportive elements of online health forums,^{29–31} this study found that not only do users use online health forums for supportive aspects but also to fill informational gaps that are not addressed by HCPs.

There are several limitations to this study. Analysis was based upon posts specifically about heart failure in publicly available online health forums, within a limited timeframe (2016–2019). Selecting another time frame for analysis may have yielded different health conversations and using a different subject matter may have elicited different types of responses. The posts analysed were anonymous, carrying few details about the user and, therefore, yielded limited socio-demographic data, and thus the perspectives noted may not be representative of the general population. Nonetheless, this study is novel and was underpinned by a robust conceptual framework, NPT, which was a key strength of this study. Normalization Process Theory provided an important foundation to analyse and interpret the data and helped to explain key issues and processes identified through analysis of the data collected.

Future research could examine a broader range of online health forums and consider direct interaction with users to gain their perspectives. Assessing the benefits/risks of moderated online health forums, which have the potential to reduce the spread of misinformation³² vs. unmoderated would also be beneficial. Further work should explicitly examine whether online health forums do promote distrust in HCPs, and if so, how best to address this issue.

Importantly, this research shows that HCPs and healthcare systems are still not adequately meeting the healthcare information needs of people with possible or confirmed heart failure³³ and that online health forums serve an important role in supporting such individuals. This suggests greater emphasis should be placed on providing HCPs with support, and the systems and resources to better address the healthcare information needs of people with heart failure, including access to reliable online health resources.

Conflict of interest: none declared.

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