

Health information behaviour of rare disease patients: seeking, finding and sharing health information

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Abstract

Background: Rare disease patients find independent health information seeking necessary due to the general lack of knowledge on rare diseases and inadequate information provision by health care professionals.

Objective: The aim of this study is to describe distinctive aspects of health information behaviour of rare disease patients and specific challenges they face when seeking health information.

Methods: A qualitative research approach was employed including semi-structured interviews that were analysed using thematic analysis. Fifteen respondents suffering from three different rare diseases participated in the study.

Results: Health information behaviour of rare disease patients is characterised by independent and continuous health information seeking and sharing. Connecting with other patients and getting realistic insight into the condition after diagnosis, advice for everyday life, comfort and hope and confirmation that their symptoms are 'normal' are of particular importance. Lack of specific advice for daily life, inaccessible new knowledge, lack of information about drugs and encountering severe health information are common challenges patients face due to insufficient support from health care professionals.

Conclusion: Health information seeking and sharing are important aspects of rare disease patients' everyday life. Challenges they face could be overcome in cooperation with patient support groups, health care professionals and health information professionals.

Keywords: communication; information needs; information seeking behaviour; interviews; research, qualitative

Key Messages

- Rare disease patients need guidance and support in their information seeking endeavours, and they see health care professionals as allies in overcoming their information seeking challenges.
- Information coming from peer patients is of special importance, and it should be highly available.
- Health care professionals and patients' associations should encourage patients to connect and share health information, and educate them in evaluating information they find in cooperation with health information professionals.
- Qualitative research of information sharing practices of rare disease patients is necessary for more in-depth understanding of its role in their health information acquisition.

Background

Widespread daily use of information technology has created conditions for health information to be more accessible than ever before; however, there

are groups of people who still face a variety of challenges when seeking health information. Rare disease patients are one such group. Rare diseases are those with a prevalence not exceeding five patients per 10 000 residents in Europe or five patients per 6250 residents in the US (Schieppati, Henter, Daina & Aperia, 2008). Knowledge on rare diseases, their causes and treatment options is scarce, which leads to a number of questions

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regarding the way in which rare disease patients are acquiring health information, and the challenges they encounter in the process.

Health information behaviour of rare disease patients began attracting attention in the last decade (Fox, 2010; Huyard, 2009; Limb, Nutt & Sen, 2010; Litzkendorf et al., 2016; Morgan et al., 2014; Pauer et al., 2017; Tozzi et al., 2013). Insufficient medical knowledge is a frequently mentioned problem; however, studies show that rare disease patients appreciate more non-medical advice that can be applied in their daily lives. Independently searching for health information among patients has proved to be necessary since in many cases information provided by medical professionals was inadequate. Patients were most often left to their devices in searching for the necessary health information, and in doing so, they faced difficulties as finding accurate and useful health information without expert guidance was demanding (Fox, 2010; Huyard, 2009; Limb et al., 2010; Litzkendorf et al., 2016). Pauer et al. (2017) found that the quality of rare disease information on the Internet is low and that certain information categories are not sufficiently represented. On the other side, support groups proved to be extremely valuable sources of information. Support groups, among other things, allow patients to get in touch with other patients. A study by Pew Research Center (2011) showed that when seeking health information, rare disease patients and their caregivers embrace, to a higher degree than any other group of health information consumers, private social networks – family members, friends and peer patients. Analysis of information searches of rare disease patients on the Internet shows that there is a growing interest in participating in clinical research studies and a desire to supplement or better understand information exchanged with a health care provider (Morgan et al., 2014), making information seeking an integral part of patient self-advocacy. Therefore, with this study we intend to broaden understanding of health information behaviour of rare disease patients, and the challenges they face.

Objectives

Given that available knowledge about rare diseases is scarce and that patients seek health information

on their own due to insufficient information provision by health care providers, a question that arises is how this shapes patients' interactions with health information (e.g. information seeking, information sharing, information encountering), that is, their health information behaviour.

This study aims to determine the distinctive aspects of health information behaviour of rare disease patients and the specific challenges they face when seeking health information. The specific researched questions are as follows:

- 1 What are the distinctive aspects of health information behaviour in rare disease patients?
- 2 Are there any specific challenges that rare disease patients face when seeking health information?

Methods

This research is a part of a broader study of information needs and behaviour of rare disease patients conducted in Croatia in 2013. Since the study was directed towards adult patients independently seeking health information (for their own health related information needs), the sample was narrowed down by choosing rare diseases that appear predominantly in adulthood, and for which patient associations exist within the Croatian Alliance for Rare Diseases (Hrvatski Savez za rijetke bolesti, 2017). Based on these two criteria, the sample was identified with the help of three associations for rare diseases: the Croatian Association of Patients with Scleroderma, the Association of Patients with Collagenosis and the Croatian Association of Patients with Myasthenia Gravis. As there are no comprehensive epidemiological data on rare disease patients in Croatia, the convenience sampling method was employed to obtain as many respondents as possible.

In the first phase of the study, a quantitative methodology was used in the form of a print and online questionnaire. One hundred and forty-six respondents participated (Katavić, Tanacković & Badurina, 2016). In the questionnaire, the respondents were invited to provide their telephone number if they wanted to participate in the second part of the study. Seventy-seven

(52.7%) respondents did so. In the second phase of the study, a qualitative methodology was applied in the form of semi-structured interviews. This paper reports on the findings from the second phase of the study.

For the qualitative part of the study, a purposeful sampling method was used. We sought to include subjects possessing significant experience in seeking and sharing health information, and in encountering challenges in the actual process. Moreover, we endeavoured to cover respondents evenly with respect to diagnosis and their membership or non-membership in patient associations, given that past research has shown that patient associations are an important source of information for rare disease patients.

To form a sample based on these criteria, respondents who provided their telephone numbers were arranged into three groups according to their diagnosis (scleroderma (SCD), systemic lupus erythematosus (SLE) and myasthenia gravis (MG)). These three groups were further divided into two groups according to their membership in patient associations. Singled out from these six groups were respondents who stated in the questionnaire that they often or very often seek health information, and those who often or very often encounter challenges in finding it. An additional criterion was applied relating to the number and type of sources they used when searching for

health information. The final sample for the interview consisted of 15 respondents evenly divided in terms of diagnoses (5 patients with every diagnosis) and with respect to membership in patient associations (7 members and eight non-members). For additional information on the characteristics of the respondents (R), including their diagnoses, age and gender (F/M), see Table 1.

The semi-structured interviews were conducted according to previously formulated open ended questions (Appendix 1). The interviews were conducted either in person or by telephone, lasting between 20 and 70 minutes, and were recorded with consent.

The interview data were analysed using thematic analysis, a method for identifying, analysing and reporting patterns (themes) within data (Braun & Clarke, 2006). In the first phase, codes were developed from transcribed interviews. Twelve first-order categories appeared by combining related codes. In the next phase, associations between initial categories were determined, and three-second-order categories emerged. In the final phase, by reviewing and associating related categories, two overarching themes were developed that represent aspects of information behaviour of rare disease patients present in the interviews. For coding examples, see Appendix 2 which lists a sampling of analysed interview data.

Table 1 Characteristics of the respondents

Respondent	Diagnosis	Gender	Age	Time passed since the diagnosis in years	Patient association member
R1	MG	F	31–40	7	Yes
R2	MG	F	31–40	4	No
R 3	MG	F	51–60	5	Yes
R4	MG	F	21–30	3	No
R5	MG	M	31–40	15	No
R6	SLE	F	51–60	12	No
R7	SLE	F	21–30	12	No
R8	SLE	F	31–40	4	No
R9	SLE	F	61–70	17	No
R10	SLE	F	31–40	10	No
R11	SCD	F	31–40	21	Yes
R12	SCD	F	51–60	8	Yes
R13	SCD	F	61–70	1	Yes
R14	SCD	F	51–60	3	Yes
R15	SCD	F	51–60	2	Yes

Results

Our findings were grouped into two overarching themes: 'Everyday Life Health Information Seeking' and 'Information Solidarity: Health Information Sharing'. The thematic map (Figure 1) and Table 2 present findings that will be discussed in turn.

THEME 1: everyday life health information seeking

The first overarching theme, with its three thematic categories ('Independently Seeking Health Information', 'Challenges' and 'Connecting'), is related to specific aspects of seeking health information in everyday life.

Second-order category 1: independently seeking health information. Respondents talked about the necessity of independently seeking health information, at first after diagnosis and later on continuously during their life with the condition.

First-order category 1: seeking health information after diagnosis. All respondents ($N = 15$) searched

for health information independently after getting the right diagnosis. The great majority of respondents explained that they were urged to search because they were not given enough, nor the right type of information from their health care providers ($N = 12$). Respondents used different hyperbolic and metaphoric expressions to illustrate the time and effort they had invested in seeking information at first: 'the struggle of gathering information' (SCD, F, R14), 'combing through all possible webpages' (MG, F, R3), 'I roamed wherever I could' (MG, F, R4) and 'manic digging around' (SLE, F, R10). The first information need for most of the respondents was related to prognosis and outcome ($N = 10$), and for some mortality ($N = 3$). Respondents wanted to know whether they would survive and whether they would be able to live with the condition.

'First of all, [I wanted to know about] mortality [. . .] Then, of course, I was concerned if I will be able to function within my family, and in my workplace, which proved impossible for me.' (MG, F, R1)

While some respondents thought their health care providers had given them too harsh a version of the

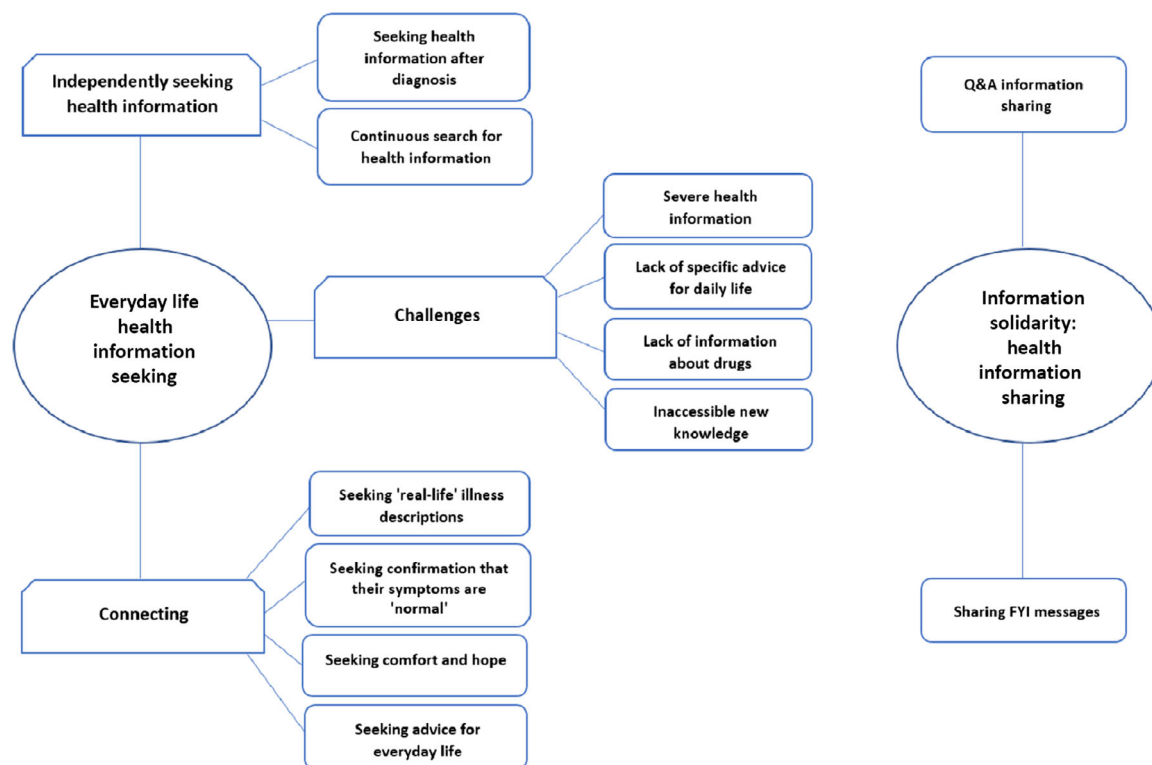


Figure 1 Thematic map [Colour figure can be viewed at wileyonlinelibrary.com]

Table 2 Themes and categories with respect to diagnoses and PA (patient association) membership

Themes	Second-order categories	First-order categories	Total	MG		SLE Non- members (N = 5)	SCD PA members (N = 5)
				PA members (N = 2)	Non- members (N = 3)		
Everyday life health information seeking	Independently seeking health information	Seeking health information after diagnosis	14	2	3	5	4
		Continuous search for health information	8	1	2	1	4
	Challenges	Lack of specific advice for daily life	11	2	2	4	3
		Inaccessible new knowledge	5		1	1	3
		Lack of information about drugs	10	1	2	4	3
		Encountering severe health information	8		1	3	4
	Connecting	Seeking 'real-life' illness insights	6		1	3	2
		Seeking comfort and hope	8	1	1	3	3
		Seeking confirmation that their symptoms are normal	4		2	2	
		Seeking advice for everyday life	10	2	3	3	2
Information solidarity: health information sharing		Q&A information sharing	10	2	3	3	2
		Sharing FYI messages	5	1	2	1	1

condition without much sympathy ($N = 5$), others felt that they had been given too light a version, and they experienced discomfort when seeking information independently ($N = 6$). Respondents had a unified view that they want comprehensive, complete and objective information from health care providers ($N = 9$), but presented with compassion and encouragement ($N = 11$).

First-order category 2: continuous search for health information. The continuous search for health information appeared as a common behaviour among some respondents ($N = 8$). Respondents explained that the most intensive information seeking period was after getting the diagnosis. Later on, information seeking in daily life happened when they encountered new symptoms, new medications or new side-effects. On the other hand, information seeking was sometimes prompted by the feeling 'whether I can still dig up something else'. (SCD, F, R11) caused by the lack of knowledge about the condition. Therefore, the continuous search for health information can either be pragmatic or simply

generated by curiosity. In the second case, patients want to know about the latest news.

'All the latest in that field, that's what we who have myasthenia are most interested in. We've all got more or less the basic information, and now just the latest news. Have they discovered a cure and the cause.' (MG, F, R3)

Second-order category 2: challenges. First-order category 3: lack of specific advice for daily life. In general, respondents had no problems with finding basic information on their conditions, but the available information was 'scarce', 'uniform', 'generic' and primarily relating to medical aspects of the conditions ($N = 11$). The lack of health information applicable to managing their condition in everyday life was highlighted as the primary shortcoming of health information sources that respondents used when searching for health information.

'In my opinion there is no adequate information at all. [...] There is nothing that would be some

guideline, so that you can behave accordingly.’ (SCD, F, R14)

A few respondents mentioned problems with accessing information on their social rights, such as the right to sick leave, disability benefits and early retirement ($N = 4$).

First-order category 4: inaccessible new knowledge. One of the possible solutions to the lack of health information is following updates on new studies which may shed more light on the causes and the treatments of the condition. This information was seen as having a possible practical application, and as giving hope and being ‘the light at the end of the tunnel’ (SCD, F, R15). However, new information was hard to find ($N = 5$), as it can only be obtained through specialised medical sources which are either not accessible through open access or not available in the Croatian language and contain expert medical jargon.

This problem was especially experienced by patients with SCD ($N = 3$). Since there is no effective treatment for this condition, patients are in constant need for any information available on treatment and self-help. Patient associations are trying to provide this information to members, but they do not have access to expert information that could widen their scope of understanding, since such information is not customised in terminology and content to their needs. Exceptionally challenging for patients was ‘translating’ medical information, medical papers or symposium presentations into something useful that could guide their behaviour. This is where the assistance of medical professionals becomes necessary because ‘As patients [...] we can’t grasp the medical terms that doctors can.’ (SCD, F, R14)

First-order category 5: lack of information about drugs. Two main reasons were mentioned for insufficient information on drugs. First, respondents were not given enough information about drugs from medical doctors ($N = 7$), and second, for some medications there is no available information in the Croatian language, not even in drug packaging ($N = 4$). Respondents primarily talked about lack of information about drug

indications and side-effects, and using the internet, forums or fellow patients for resolving their issues in this context.

Some problems with drug information accessibility are more typical for some diagnoses. For example, searching independently for information about drug interactions was mentioned as a problem by patients with MG (R5). Dispersion of information in different places, lack of information in Croatian and medical jargon were mentioned as main obstacles in the searching process.

‘It’s more or less difficult to get that kind of information [about drug interactions]. Our drug names and foreign drug names, decrypting what it means, which is generic, which original, which is what, that’s a fright! [...] I have to drag that information from brochures, then digging on the Internet, a bit here, a bit there and that’s literally hell!’ (MG, M, R5)

Patients with SCD, on the other hand, experienced problems with lack of information on drug indications and effectiveness. As already mentioned, there is no effective treatment for this condition and it comes down to ‘trying-out modes if your body will respond to the drug or not’. (SCD, F, R14) However, patients were not well informed about the purpose of taking different drugs, nor instructed from their doctors on how to track their reactions to drugs ($N = 2$).

‘...what is important is getting information on what drugs really work, and what is some sort of placebo. That kind of information is impossible to find and, of course, you will not get that information from doctors, but honest doctors will say - we’re going to try.’ (SCD, F, R14)

A few respondents mentioned that they had discovered new drugs on forums or Facebook groups that their health care providers had not mentioned to them ($N = 3$).

First-order category 6: encountering severe health information. Respondents described encountering severe health information as a negative consequence of health care providers offering

insufficient information. Coming across severe information generated additional questions to which respondents could not find answers on their own. Consequently, they felt that health care providers need to provide complete and realistic information in a considerate manner. Patients with SCD and SLE ($N = 8$) predominantly mentioned this problem.

‘What do you get, the first information when you type into a search engine? You get people with an absolute deformed appearance, a lion’s face, people shown with their hands in contractures and amputations of partial fingers [...]. Therefore, you get absolutely all of the most negative information. [...] If we got some feedback from the physicians on the insights they have, were it in some way accessible, simple, and presented to patients in a human manner, it would be then easier.’ (SCD, F, R14)

On the other hand, respondents suffering from MG mentioned the opposite problem – the lack of information about severe problems in the available descriptions of the condition (R4, R5). Respondents, on the one hand, did not recognise some of their symptoms within standard descriptions of the condition, while on the other hand, they felt that their family, friends and colleagues reading about their condition could not get a genuine picture of the problems they face in their everyday life. They, therefore, considered it necessary to extend descriptions of the disease not only because of them, but because of people around them.

Second-order category 3: connecting

The third and last thematic category within the theme ‘Everyday Life Health Information Seeking’ deals with seeking fellow patients’ experiences of illness.

First-order category 7: seeking ‘real-life’ illness descriptions. After being diagnosed, a great majority of respondents were primarily interested in the outcome of the condition and how it influences everyday life. Since available information on websites was medical, scarce and generic, patients shifted their attention to seeking

experiences of other patients in order to gain a more ‘realistic’ picture of the condition ($N = 6$).

‘I was interested in the outcome, what happens in the end in real life, was someone cured, whether someone experienced withdrawal...’ (SLE, F, R8)

Respondents specifically mentioned stories of patients who have more or less successfully faced the same diagnosis as being important for them at first.

‘I remember digging up stories about other people with lupus. I read about a woman who has had lupus for thirty years and that encouraged me, only then did I realise that lupus does not mean a death penalty, and only then did I begin to reconcile with the diagnosis.’ (SLE, F, R10)

While some respondents found patient stories online, other patients got first ‘real-life’ insight into the condition when coming to the patient association for the first time ($N = 2$).

‘At the first patient group meeting for the first time I felt that there was someone like me, and that I could get some answers there [...] They [other patients] looked normal, came on their own feet, they were not disabled, and they did not look the way I saw on the Internet. [...]’ (SCD, F, R15)

First-order category 8: seeking comfort and hope. Besides getting a realistic picture of the condition from other patients, respondents also found comfort in the fact that there are others like them and that there are people who more or less successfully cope with their diagnosis ($N = 8$). As we have shown, for many of them, reading other patients’ experiences or meeting other patients helped them to cope with the diagnosis at first.

‘Testimonies have probably helped me the most where people speak about feeling bad and others not understanding them. There are real stories where people testify about it, talking about difficulties they have, how people reacted, how physicians treated them. Somehow you identify with them, you realise you’re not alone.’ (MG, F, R4)

First-order category 9: seeking confirmation that their symptoms are 'normal'. Respondents mentioned that other people's experiences give them a confirmation that they are 'normal', confirming that the symptoms they are experiencing are real ($N = 4$). This was especially true for patients whose symptoms were unusual, or significantly impaired the quality of their life. Furthermore, only patient association non-members mentioned seeking confirmation that their symptoms are 'normal', indicating that members spontaneously receive this confirmation from interacting with other patients.

'I find it exceptionally important to see that other people go through what I do, and that I'm not insane. That I'm really seeing double, that I'm really not able to comb my hair, that I'm not imagining not being able to stand on my feet. And I see that other people are going through the same, I'm not imagining it, and then I can say OK, I'm normal.' (MG, F, R4)

'It's interesting to communicate perhaps not so much about the illness [...], but how it influences daily life, that's more interesting, and what problems they face, because for example I've often been mistaken in public for being drunk, drugged, like this or that.' (MG, M, R5)

First-order category 10: seeking advice for everyday life. Seeking health information from other patients happens either indirectly through reading recorded posts on forums or social networks or directly by contacting forum or social network members, or personal acquaintances with the same diagnosis ($N = 10$). Respondents reasoned that precisely because they suffered a rare and unusual disease, accompanied by many various symptoms, 'any information from another patient was handy.' (MG, F, R1)

'[...] examples of other people [are source of advice for life], then I draw some lessons out of them. On some forums or something, you see how others face some issues, and adjust that to yourself.' (MG, F, R1)

Patients talked about seeking information relating to problems they face in their daily life (symptoms,

drugs, side-effects etc.). Although respondents primarily talked about the positive aspects of being able to seek and receive advice from fellow patients, some mentioned the problem of decision-making based on individual experiences ($N = 3$).

Contact with fellow patients appeared to be an important source of serendipity. Respondents talked about 'discovering' new medication, health advice and patient associations by chance during the contact with fellow patients ($N = 6$).

THEME 2: information solidarity: health information sharing

Health information sharing, as a second overarching theme, appeared in the interviews with respondents who are either active in online groups or in patient associations.

Since our sampling method did not aim specifically to include posters in online communities, not many posters were among the interviewed group ($N = 4$). Therefore, part of our findings come from interviews with members of online communities who talked about using the information other posters have shared with them. Furthermore, there is an overlap to a certain extent with the second-order category 'Connecting' which deals with seeking fellow patients' experiences of illness. However, these topics are naturally intertwined and give us insights into both the practice of seeking and sharing information. Nevertheless, due to a relatively small number of posters, results relating to health information sharing should be regarded as preliminary.

Patients talked about two types of health information sharing based on sharing motivations:

- 'Q&A (Question and Answer) Health Information Sharing'
- 'Sharing FYI (For Your Information) Messages'

Both types of information sharing encompassed sharing first-hand experiences and sharing medical information.

First-order category 11: Q&A (question and answer) health information sharing. Q&A information sharing referred to sharing answers to specific queries other patients asked either in person ($N = 3$) or online ($N = 7$). Respondents shared information on dealing with specific everyday life

health challenges relating to 'the small things that make everyday life easier'. (SLE, F, R6)

'I get a lot of information from life situations. I ate Griote, those with punch, and I didn't feel good. You send an enquiry, a question, and then you realise that I'm not supposed to take alcohol, but the doctor never said anything. [...] There are a lot of things which I discovered on Facebook.' (MG, F, R4)

Health information sharing was helpful in decision-making on treatment as well. A few respondents stated that they had changed their choice of medication, based on the recommendations they got from other patients on forums or Facebook.

'I got, for instance, a prescription for Resochin, however the girls on the forum said that Resochin has the most side-effects, it aggravates the eyes and then the replacement is Quensyl. My doctor has never heard of Quensyl, so she was surprised when I said that I'd rather have that.' (SLE, F, R6)

Sharing information online creates a written record available for public use, which appeared to be a source of serendipity for patients active online.

First-order category 12: sharing FYI (for your information) messages. Besides health information sharing as a response to specific inquiry, another type of health information sharing was observed. This type of information sharing is motivated by a general sense of solidarity with others who find themselves in similar situations. These are the FYI (for your information) messages sent with no precise recipient in mind and with the particular intention of hopefully providing useful information to someone who may need it ($N = 5$).

'What's most important is living with the condition [...] I like to read those specific things, and often I'll write a lot about anything. I write what I consider to be useful for others.' (MG, M, R5)

'I think someone will find useful if I post something I've found useful. It's usually something I find. [...] a simple act of solidarity.' (SLE, F, R10)

Respondents who were active users of online communities cited that posting health information on their condition was a common practice among active members. Respondents shared health information that they found or got at their disposal, or personal experiences on self-help methods, treatments, medication, health care and the like.

'If someone comes across some information, something new, something interesting, he uploads it, a small link and we all have a look.' (MG, F, R4)

'For me the illness went into remission during pregnancy, and I wrote about it to encourage others. It's nothing special, but it could help someone to see that there are positive examples.' (SLE, F, R10)

In addition to health information sharing online, respondents shared information in print form as well. This appeared among the members of patient associations who are generally aware that people with rare diseases encounter many difficulties when trying to get a proper diagnosis. It is precisely because of these people who might be struggling with symptoms of their diseases, that patient association members disseminate information booklets from their associations in waiting rooms at local health centres and hospitals during patient check-ups in the hope that they will help people who have the symptoms of their disease, and may not even be aware of it.

'We as members go to meetings, then we stack up on brochures and then leave them in hospitals where we go, where we think it would be good to leave them. And they always disappear, meaning that someone takes them. Those brochures help some to get diagnosed more easily, that in the case of scleroderma is very important.' (SCD, F, R11)

Discussion

Due to scarce knowledge about rare diseases and insufficient information provision by health care providers, many information needs of rare disease patients are unmet and patients are often forced to

seek health information on their own. For many patients, personal contacts, either through patient associations or online, played a major role in information acquisition (Fox, 2010; Huyard, 2009; Limb et al., 2010; Litzkendorf et al., 2016; Morgan et al., 2014; Pauer et al., 2017; Tozzi et al., 2013). Our findings are consistent with the results of previous studies, but provide additional insights into information behaviour of rare disease patients, and especially the role of connecting and peer-to-peer information sharing.

Our findings were grouped into two themes: 'Everyday Life Health Information Seeking' and 'Information Solidarity: Health Information Sharing'.

The first theme related to specific aspects of seeking health information in everyday life, and it encompassed three thematic categories: 'Independently Seeking Health Information', 'Challenges' and 'Connecting'.

We know from previous studies that patients actively engage in seeking health information right after diagnosis with disease prognosis being their primary information need at first (Fox, 2010; Limb et al., 2010; Litzkendorf et al., 2016; Morgan et al., 2014; Tozzi et al., 2013). Our study confirms this, but shows as well that the chronic nature of rare conditions, not knowing their causes, and not having a specific cure, is motivation for seeking health information continuously. While for some rare disease patients their health issues prompt information seeking, for others it is their wish to be informed about the latest news. Identified challenges in health information seeking to a large extent arose from the fact that health care professionals did not have adequate communication with patients. Health information for everyday life was especially important. However, that kind of information was exactly what was missing. Following updates on new studies which may bring forth information with possible practical application in everyday life was seen as one of the possible solutions. However, patients were not able to recognise and extract this information on their own, but they needed the assistance of medical professionals. The same broad conclusion relates to information about drugs and encountering severe information. Patients need guidance, advice and support in their

information seeking endeavours. Recently published literature review regarding emerging and evolving roles of health information professionals identified both clinical and medical information provision, and patient support and advocacy as one of the foremost roles of health information professionals (Ma, Stahl & Knotts, 2018). While medical professionals have unquestionable authority regarding health information interpretation, health information professionals could serve as intermediaries in finding, organising and providing health information to rare disease patients.

For rare disease patients, the support of peer patients plays a major role in information acquisition (Fox, 2010; Limb et al., 2010; Litzkendorf et al., 2016). Patients can provide information, emotional and social support by sharing information (LaCoursiere, 2001) and studies show that outcomes of peer-to-peer information sharing are predominantly positive in terms of dealing with illnesses, making medical decisions etc. (Ziebland & Wyke, 2012). We have identified several reasons for connecting with fellow patients: gaining realistic insight into the condition after diagnosis; seeking advice for everyday life; seeking comfort and hope and seeking confirmation that their symptoms are 'normal'. We know from previous studies that patients in general appreciate other patients as information providers simply because, as de Bronkart (2011), a patient cured from a rare type of cancer, explained during his speech at a Technology, Entertainment, Design conference – 'Patients know what patients want to know'. Contact with fellow patients seemed to be an important source of serendipity. Respondents talked about 'discovering' new medication, advice and patient associations during the contact with the fellow patients. In the LIS literature, serendipity is a well-documented phenomenon (Erdelez, 1999; Toms, 2000; Williamson, 1998), and in the health context, a common way of getting health information in everyday life of ordinary citizens (Pálsdóttir, 2010). For rare disease patients, other patients play a major role, not only in their information seeking endeavours, but in the serendipity context as well. The importance of patient associations in this study is

illustrated not just by explicit referrals to the membership benefits, but also by the fact that no patient association members in this study mentioned seeking confirmation that their symptoms are 'normal', indicating that they spontaneously get this confirmation from interacting with other patients in patient associations.

Within the second overarching theme 'Information Solidarity: Health Information Sharing', two types of health information sharing were observed: 'Q&A Health Information Sharing' and 'Sharing FYI Messages'. 'Q&A Information Sharing' referred to sharing answers to specific queries other patients asked online or in person, while FYI sharing referred to distributing information online or in print with no precise recipient in mind, but with the intention of hopefully providing useful information to someone who may need it. We know that two categories of users participate in online communities – information providers and information users, also more commonly called posters and lurkers (Mo & Coulson, 2010). Our results are in line with the knowledge that there are 'Initial Posters' who ask new questions or raise new issues (Walker, Redmond & Lengyel, 2010). Several respondents found a greater purpose in sharing information with others. This should be acknowledged and encouraged for mutual benefit of both posters and lurkers.

Conclusion

Information seeking and sharing appear to be common coping strategies for rare disease patients. However, due to many challenges that they face when acquiring health information, patients need guidance and support, and they saw health care professionals both as a source of their unsatisfied information needs, but also as possible allies in discovering and presenting health information. Information coming from peer patients is of special importance, and it should be highly available. Moreover, this information should be organised according to patients' needs: gaining realistic insight into the condition after diagnosis; advice for everyday life; comfort and hope and confirmation that their symptoms are 'normal'. An

interesting finding is that there are patients who find satisfaction and fulfilment in being the information source for other patients. Therefore, patients should be encouraged to connect and share health information. Also, since rare disease patients rely so extensively on the Internet for health information, and on other patients' experiences, it would be beneficial to educate patients about seeking and evaluating health information online. Although there are many positive aspects of using health information found in online communities, patients can be overwhelmed and confused when trying to decide which information is relevant for them (Nath, Huh, Adupa & Jonnalagadda, 2016). Health information professionals, medical professionals and patient groups could join forces in educating and supporting patients in health information seeking, and in finding, organising and providing health information to patients.

No matter which aspect of the information behaviour of rare disease patients we are referring to, one thing is crucial, and that is cooperation. Patient associations and medical professionals should be aware that rare disease patients actively engage in information seeking and sharing, and provide their professional support and guidance to patients in this field as well.

Limitations and future directions

This study is not completely empirically generalisable due to several reasons. The number of rare disease associations in Croatia is limited, making up the sample in this study involving patients suffering from three rare diseases. It would be beneficial to confirm results of this study using a wider sample of patients suffering from various rare diseases. Furthermore, diseases included in this study predominantly affect the female gender which is reflected in our sample. It would be interesting to further study how male sufferers seek and share health information. Also, part of the results relating to health information sharing online should be taken as preliminary due to the low number of posters in online communities.

Qualitative methodology using retrospective recall of information needs and behaviour by study participants is subject to unintentional omissions

and errors. It would be beneficial to further study questions that rare disease patients ask in online communities as these questions represent information needs in real life (Oh, 2015).

Acknowledgements

Author would like to acknowledge Jadranka Brozd, Dubravka Čizmić and Jadranka Delija, presidents of patient associations that participated in this study and the contribution of the study participants.

Conflict of interest

Author declares no conflict of interest.

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Received 14 June 2017; Accepted 30 March 2019

Appendix 1

Interview questions

- 1 When did the first symptoms of your illness appear and how long did it take to determine the correct diagnosis?
- 2 Can you remember what health information you received from a medical professional when diagnosed with the rare condition?
- 3 Were you satisfied with the amount and the type of health information you received from your doctor when diagnosed with the rare condition?
- 4 What were you most interested in when diagnosed with the rare condition?
- 5 Were you independently seeking information about the diagnosis after you were diagnosed with the rare condition?
- 6 Where did you seek health information?
- 7 Did you manage to find the health information you needed?
- 8 How did you feel about the health information you were coming across?
- 9 How often do you nowadays seek health information regarding your rare condition?
- 10 In what situations do you seek health information?
- 11 Where do you usually look?

Appendix 2

Coding examples

Respondent	Interview quotations	Codes	First-order categories	Second-order categories	Themes
2	<i>There is no instruction on Mestinon in Croatian, in the pill box. Then, when I got this medicine, I used Google translate to inform myself about it.</i>	Not available drug instruction in Croatian Using Google translate for information about medicine	Lack of information about drugs Continuous search for health information	Challenges Independently seeking health information	Everyday life health information seeking
4	<i>The instructions for Mestinon are in German. I do not speak German. But I somehow grapple with it on the Internet. Moreover, no one has ever told me that a diabetic is not allowed to take this medication, but I found about it accidentally. I'm not diabetic, thank God, but I think someone should have told me about this. I discovered on Facebook that in fact there is a nightly Mestinon which no one mentioned to me, with less and gentler alleviation, it is not available in Croatia but you get it from abroad. If a doctor prescribes me a medicine, it's important to me to know why I take this medicine, what it is, but that information I did not get. It's more or less difficult to get that kind of information [about drug interactions]. Our drug names and foreign drug names, decrypting what it means, which is generic, which original, which is what, that's a fright! [...] I have to drag that information from brochures on myasthenia, then digging on the Internet, a bit here, a bit there and that's literally hell! Because I didn't study medicine and I don't know where to start, and there are a lot of possible interactions between drugs.</i>	Not available drug instruction in Croatian. Using Internet to find information about drugs. Doctors not informing patients about drug contraindications. Discovering drug information on Facebook group.	Lack of information about drugs Continuous search for health information Lack of information about drugs Seeking advice for everyday life	Challenges Independently seeking health information Challenges Connecting	Everyday life health information seeking Everyday life health information seeking Information solidarity: health information sharing
5		Doctors not informing patients about drug indications. Difficulties in finding information about drugs interactions.	Lack of information about drugs Continuous search for health information	Challenges Independently seeking health information Challenges	Everyday life health information seeking

(continued)

Appendix 2 (Continued)

Respondent	Interview quotations	Codes	First-order categories	Second-order categories	Themes
6	<i>I got, for instance, a prescription for Resochin, however the girls on the forum said that Resochin has the most side-effects, it aggravates the eyes and then the replacement is Quensyl. My doctor has never heard of Quensyl, so she was surprised when I said that I'd rather have that.</i>	Seeking information about drugs on forum. Doctor not informed about it.	Seeking advice for everyday life	Connecting	Everyday life health information seeking Information solidarity: health information sharing
7	<i>Doctor prescribes me Imuran and the only thing that he explained to me is that Imuran is cytostatic, which does not mean anything to me. So, I had to search for explanations on my own.</i>	Doctors not informing patients about drug indications.	Lack of information about drugs	Challenges Independently seeking health information	Everyday life health information seeking
10	<i>I used forum when I was having side effects because of the therapy I had been taking, since this kind of information is difficult to find, about what is normal, and what is not and how you can help yourself. Drug instruction is in German, and I do not speak German, but fortunately I have one acquaintance who takes this medicine as well, so I asked her about her experience.</i>	Hard to find information on drugs side-effects. Seeking advice about drugs on forum. Not available drug instruction in Croatian Seeking advice about drugs from fellow patient.	Lack of information about drugs Seeking advice for everyday life Lack of information about drugs Q&A (question and ask) health information sharing	Challenges Connecting Challenges	Everyday life health information seeking Information solidarity: health information sharing
11	<i>One of my colleagues has lupus and she has taken antimalarial, Resochin for years. Doctors never told her to stop drinking it, and she went blind from it! And when you take Resochin, drug instruction is only in German. If I knew what Decortin was doing to the body and that I could get diabetes, I would not go to those infusions. And well, I went and now I have diabetes from all those corticosteroids.</i>	Doctors not informing patients about drug side-effects. Not available drug instruction in Croatian Doctors not informing patients about drug side-effects.	Lack of information about drugs	Challenges	Everyday life health information seeking

(continued)

Appendix 2 (Continued)

Respondent	Interview quotations	Codes	First-order categories	Second-order categories	Themes
14	What is important is getting information on what drugs really work, and what is some sort of placebo. That kind of information is impossible to find. And, of course, you will not get that information from doctors, but honest doctors will say - we're going to try -, because scleroderma treatment is basically trying-out modes if your body will respond to the drug or not.	Doctors not informing patients about drug indications and effectiveness.	Lack of information about drugs	Challenges	Everyday life health information seeking
15	She [doctor] told me to take three types of medications for which I did not get any clarification on what these medications were and why should I take them. Actually, everything more concrete that I wanted to know, I has to search for myself.	Doctors not informing patients about drug indications.	Lack of information about drugs	Challenges Independently seeking health information	Everyday life health information seeking