The response of patient organizations to the first phase of the COVID-19 pandemic: A qualitative study in Latvia

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> Abstract. Patient organizations have proven to be crucial stakeholders for patient needs in the health system. However, the global health crisis due to the emergence of COVID-19 has affected the routine of organizations. This qualitative study explores the experience of patient organizations in adapting their services to the situation during the first phase of the COVID-19 pandemic in Latvia in Spring-Autumn 2020. Fifteen chairpersons of patient organizations were recruited and interviewed using a semi-structured key informant interview. The interviews were recorded, transcribed, and thematically analyzed with manual thematic coding. Four main themes were identified: information needs on COVID-19; diversification of communication channels and their adjustment to the COVID-19 situation; continuity of routine management of patient organization; support mechanisms for patient organizations in the context of the COVID-19 pandemic. Patient organizations experienced a rapidly changing environment as a result of COVID-19 and have had to react immediately to ensure the provision of the service to the patient community they serve.

1 Introduction

Patient organizations are strengthening their role as stakeholders in patient-centred healthcare, ensuring that patient voices are heard in a clinical environment and health policy decision-making [1]. Patient organizations fulfil the task of ensuring education, information, and support for patients [2]. All these tasks were put to the test during the COVID-19 pandemic and required patient organizations to adapt to the new and growing needs for patient advocacy [3-5].

Recent findings on the impact of the COVID-19 on the operation of patient organizations have found adverse effects. Patient organizations experienced a significant decrease in funding [3, 4] and faced financial difficulties, as they functioned at reduced capacity with fewer organizational activities [5]. At the same time, the general workload had increased due to increasing patient requests for support [5]. Many organizations have had to alter their routine services for people. They began to produce new information related to COVID-19, developed new services, and moved existing services online [4].

Patient organizations experienced an increase in phone calls and e-mails [3, 4], as well as an increase in the average length of these phone calls [6]. The digitization of operations and communication was used as a solution to ensure continuity of patient support [5]. However, rapid and intense reliance on technology raised the issue of technical accessibility and digital literacy [4].

In Latvia, as elsewhere in the world, routine life was affected by the COVID-19 pandemic. This study aimed to obtain qualitative data on the impact of the COVID-19 pandemic on patient organizations and to describe how patient organizations responded to the challenges of the pandemic. The study explored the experience of patient organizations in adapting their services to the situation specifically during the first phase of the COVID-19 pandemic in Latvia in Spring-Autumn 2020.

2 Methods

This study is the qualitative component of a larger mixed-method study exploring the impact of the COVID-19 pandemic on the health system and public health in Latvia.

2.1 Research design

The applied qualitative research design was chosen to address the aim of this study. In public health, the applied approach illuminates the pragmatic nature of qualitative research and helps generate useful and applicable knowledge for specific practical purposes that can be effectively used to address current problems of concern [7, 8].

2.2 Sampling and recruitment of participants

A purposive sample of key informants included chairpersons of Latvian patient organizations representing patients with chronic diseases (cardiovascular, endocrine, oncologic, neuromuscular, various rare diseases, HIV and viral hepatitis, rheumatologic etc.).

The main inclusion criteria were: 1) voluntary consent to participate in the study; 2) a chair of the Latvian patient organization, representing patients with chronic disease; 3) the patient organization is included in the Latvian patient organizations network [9] or the Latvian Alliance for Rare Diseases [10].

Participant recruitment occurred through the Latvian patient organizations network, which unites more than 30 Latvian patient organizations [9]. The participation invitation letter was sent to the publicly available official email addresses of patient organizations. The letter explained the purpose of the study and why the invited are being chosen. It also contained informed consent to sign. In total, 20 invitation letters were sent to potential participants. As a result, 15 chairpersons from 15 Latvian patient organizations agreed to the interview and, therefore, were included in the study sample.

2.3 Data collection

A semi-structured key informant interview was used as a qualitative data collection method. Data were collected between September 2020 and January 2021. The key informants were interviewed face to face (n = 3); on the Zoom or Skype platform (n = 8) or by telephone (n = 4) by three interviewers (LS, RP, MK). Members of the research team developed a semi-structured interview guide with experience in qualitative methodology (IS, LS) and public health (LS, MK, AV) to ensure the focus of the interview and the fulfilment of the research

purpose. The questions were open-ended and flexible enough to encourage participants to discuss their experiences. The main questions asked were: 1) 'How did the routine operation of the patient organization change during the first phase of the COVID-19 pandemic in Latvia in Spring-Autumn 2020'; 2) 'What were the challenges in ensuring the daily operation of the patient organization'; 3) 'How did the organization provide support to its patients during COVID-19'; 4) 'What coping strategies were used to continue the operation of the patient organization under COVID-19'; and 5) 'What are the main lessons learned'. The probe questions (for example, 'please tell me more about that'; 'can you give me an example of that'; 'can you give me more details'; 'how does this affect'; 'what alternatives are there') were used when needed to improve the richness and intensity of the interview.

All participants signed the informed consent before the interview started. Participants were informed about confidentiality and their right to withdraw participation at any time for any reason. With the permission of the participant, the interviews were recorded and lasted 20-80 minutes (mean 42 min). The audio recordings were transcribed verbatim by a member of the research team (RP). All identification information was removed from the transcripts and numbers assigned instead of names (e.g., participant P01; P02, etc.).

Ethical approval for this study was received from the Ethics Committee of Riga Stradins University (Nr. 6-1/08/9).

2.4 Data analysis

Thematic analysis [11] was used to analyze the data. Thematic analysis was chosen since it allows the researcher to see and make sense of collective or shared meanings and experiences about a specific phenomenon [12]. Through thematic analysis, the researcher can systematically identify, organize, and report broader ideas, repeated topics, or common themes that are represented in a data set [11]. Here, themes are actively constructed patterns that reflect the main features of the data set and capture crucial information about the research questions [11, 13]. As noted by Braun and Clarke [14], thematic analysis offers a useful qualitative data analysis approach for researchers conducting more applied research in health contexts. The coders followed a six-step process proposed by Braun and Clarke [11]: (1) familiarization with the data, (2) generation of initial codes, (3) search for themes, (4) review themes, (5) definition and naming themes, and (6) production of the report. The transcriptions were independently coded by two researchers (IS, RP), and then the codes were compared and discussed in team meetings. A research team approach (LS, RP, IS, MK, AV) was used to identify, review, and define the main themes, related subthemes, and their interpretations collectively until a consensus was reached.

3 Results

After thematic data analysis, 4 main themes and 11 subthemes were identified. Each theme highlighted a unique aspect of the impact of the COVID-19 pandemic on patient organizations during the first phase of the COVID-19 pandemic in Latvia in Spring-Autumn 2020. The themes and related sub-themes are presented in Table 1.

Main theme	Subtheme
Information needs on COVID-19	SeekingCOVID-19 information
	Provision of COVID-19 information
Diversification of communication channels	Digitalization of communication
and their adjustment to the COVID-19 situation	Decrease in face-to-face communication
Continuity of routine management of patient organization	Ability to be flexible in management
	Long-term vs. short-term planning strategies
	Defining the future needs of patient organizations
Support mechanisms for patient organizations in the context of the COVID- 19 pandemic	Decrease in financial flow
	Demand for extra resources
	External support mechanisms

 Table 1. Patient organizations' response to the first phase of the COVID-19 in Latvia:

 themes and subthemes.

3.1 Information needs on COVID-19

During the first phase of the pandemic, patient organizations experienced an acute need for reliable information on COVID-19 to be distributed to the patient communities they serve. The chairpersons reported that their objective was to promote patients' awareness of the pandemic, educate patients, and share information on safety measures, symptoms, disease management, and the availability of health services while a state of emergency has been declared.

3.1.1 Seeking COVID-19 information

At the beginning of the pandemic, patient organizations faced a lack of the necessary and sufficient information on COVID-19. However, the organizations actively realized the search for health information: *«There was a large information vacuum; we just took the initiative to do the things that are needed now»* (Participant P04). The rapid development and constant change of information around COVID-19 were identified as the main problems in seeking COVID-19 information. The key sources of information were national health institutions, international health organizations (for example, the World Health Organization), and the mutual exchange of information between local and international patient organizations. Information was most often searched and received electronically through the Internet media (websites, emails, social media sites), and in the form of personal communication.

3.1.2 Provision of COVID-19 information

The timely provision of credible COVID-19 information in easy-to-read and understandable formats was mentioned as a priority. Although the information onCOVID-19 was constantly changing and new information appeared, patient organizations prepared and transmitted special information materials on current issues related to COVID-19 and particular chronic diseases. These materials were often translated from English, organized logically, adjusted to the health information needs of patients, and distributed through the digital media (websites, social media), emails, text messages, online chats, and even telephone conversations to share information on COVID-19 that is appropriate for people with chronic diseases.

Experts reported on the need for a more coordinated approach to the search and provision of health information in crises such as the COVID-19 pandemic. This would

allow information to be found, transmitted, and received more rapidly and increase the level of trust of patients in that information.

3.2 Diversification of communication channels and their adjustment to the COVID-19 situation

This theme refers to the change in communication platforms from site-to-distance communication. Communication channels were diversified and adjusted to the electronic environment and patient needs in the context of the pandemic.

3.2.1 Digitalization of communication

Digital communication was used as a solution to continue the exchange of information between members of the patient organization. Many types of digital communication channels were exploited: email, phone calls, short message service, web-chats, video platforms (Zoom, Microsoft Teams) etc.

In general, the participants evaluated digital communication as a good option that can intensify the exchange of information, reach a larger audience, and save time and financial resources (for example, travel costs to on-site events). At the same time, participants noted that among older patients and patients in rural areas low technology literacy, inadequate Internet connectivity, and limited access to modern digital devices (mainly, smartphones and laptops) posed a great obstacle to effective communication: *'Here we have elderly patients in the organization who have difficulty using digital technologies.'* (Participant P13) Therefore, digital communication can lead to unequal access to information, which is a significant social problem that needs to be addressed. Traditional channels of information exchange (for example, printed materials, face-to-face consultations, information available on the radio, etc.) must also be maintained, especially for people with limited access to technological tools.

3.2.2 Decrease in face-to-face communication

A rapid decrease in face-to-face communication was observed in patient organizations. This, in turn, limited regular information exchange and interpersonal contact among members of the patient organization. For example, before the COVID-19 pandemic, some patient organizations regularly provided home visits to help patients with self-care. Whereas this service was limited or unavailable during the first phase of the COVID-19 pandemic, especially during a state of emergency, deterioration in the well-being of some patients was observed. Interpersonal contact is often the motivating force for the willingness of patients to take control of their health and improve it: *'Sometimes it has to be like a golden pendulum for the patient to start moving. Because they [the patient] will do [self-care] less. In the end, they will not do it at all. That is how they will die. ' (Participant P13).*

Few participants reported that some events on-site, such as conferences, seminars and lectures, had to be cancelled due to the COVID-19 pandemic, which also led to less face-to-face communication.

3.3 Continuity of routine management of patient organization

Ensure the continuation of the routine of patient organizations during the COVID-19 pandemic was mentioned as a priority. To achieve this goal, the chairpersons of the patient organizations had to change and adjust the management style of the organization.

3.3.1 Ability to be flexible in management

The chairpersons acknowledged that they needed to be flexible in their management style. The ability to respond quickly to changing circumstances and adapt the organization's management to the dynamics of the COVID-19 situation was essential. They also noted that the content of the organization's day-to-day work changed. The provision of information to patients about COVID-19 and available healthcare during COVID-19 restrictions was prioritized. In addition, other changes in the organization (for example, the transition to digital communication, reduced financial resources, and the need for additional human resources) required a creative and flexible response. Flexibility in management was also required to find the best possible solutions to problems.

3.3.2 Long-term vs. short-term planning strategies

The chairpersons indicated that they had to shift the focus of the organization from longterm to short-term work planning strategies. Before the pandemic, the long-term goal setting and planning of activities were common among patient organizations. As COVID-19's rapidly changing environment was highly unpredictable, the chairpersons focused on solving acute and temporary problems in a shorter time.

3.3.3 Defining the future needs of patient organizations

The chairpersons identified several future needs for patient organizations that were highlighted during the COVID-19 pandemic. First, the distance-based activity mode requires improved digital competency. Second, for remote activities and digital communication, adequate provision of technology equipment is vital, as it is not available enough. Third, a more effective financial resource distribution could be implemented, because due to distance activities, some resources, such as time, fuel, and energy, were saved that could potentially be redirected to patient support.

3.4 Support mechanisms for patient organizations in the context of the COVID-19 pandemic

The theme refers to the need for additional support for patient organizations in the context of the COVID-19 crisis.

3.4.1 Decrease in financial flow

In general, a decrease in financial flow was observed in patient organizations due to the lack of fundraising events and due to the cautiousness of sponsors during the COVID-19 pandemic. The chairpersons said that they had to use the organizations' financial savings to pay the organizations' monthly payments. Some of the chairpersons mentioned that the financial situation was so critical that they even considered closing the organization.

However, the experience of some chairs showed that the day-to-day financial support of long-term sponsors, pharmaceutical companies, and entrepreneurs was not interrupted.

3.4.2 Demand for extra resources

During the COVID-19 pandemic, chairpersons of patient organizations experienced an increased demand for additional resources, mainly new digital devices; more knowledge regarding information technologies, as well as the COVID-19 virus and its effect on chronic diseases; more workers and even more working hours. They emphasized that employees work for the organization very often voluntarily, in combination with their paid work. This can lead to exhaustion.

3.4.3 External support mechanisms

The evaluation of external support mechanisms by experts was diverse. Many chairpersons reported that there was no state support during the COVID-19 pandemic. Some mentioned that they, as a non-governmental organization, were not interested in receiving any kind of support from the state because it has not been received so far, nor is there any certainty that it will ever be received. All chairs acknowledged that a lack of specific information was observed on COVID-19 and chronic diseases because the information support from state institutions did not address the needs of patients with chronic diseases. Some of the chairpersons reported that they had good cooperation with municipalities and the public sector during COVID-19 as they were proactively looking for support. Most of the experts highly appreciated mutual peer support and said that the Latvian patient organization network provided significant and useful information exchange between patient organizations.

4 Discussion

The findings of the current study explored the impact of the first wave of COVID-19 on the routine functioning of patient organizations in Latvia.

In general, as noted by the chairpersons, patient organizations sought to perform day-today activities in the face of ongoing change as much as possible. However, they faced particular challenges and obstacles. This is in line with the results of the survey reports [4, 15] and the study by Chung et al. [5] on the effect of the pandemic on the daily operation of the patient organization, where a wide range of changes and adaptations were observed.

In this study, four main areas of impact were determined and described.

First, since COVID-19 was a rapidly evolving situation during the first phase, there was an urgent need for adequate, reliable, and timely information on COVID-19 for people with chronic diseases because the pandemic has had direct and indirect effects on these people [16] and their representatives. Managing chronic diseases during COVID-19 can be difficult due to the circumstances caused by the epidemic [17]. Therefore, ensuring access to accurate information can help to manage this situation in ways that are more appropriate to the patients' health needs. Patient organizations can serve as key informants for their patients during the pandemic. The informative support they provide can help facilitate the health literacy of patients and reduce confusion in cases of rapid outbreaks of infectious diseases such as COVID-19.

In our study, the chairpersons of the patient organizations experienced a confrontation between the 'necessary' information and the 'available' information. On the one hand, patients' information needs on COVID-19, its effects on a particular chronic disease, and its treatment increased rapidly. As a result, many patients sought accurate answers from patient organizations. On the other hand, there was limited and constantly changing information related to COVID-19 at the beginning of the pandemic. Thus, the patients' information needs were confronted with the available information. To fill the information gap, patient organizations took an active initiative to search for, extract information from various sources, translate, and systematize information. Getting your information from reliable sources, such as patient organizations, is a contribution to the fight against misinformation. Additionally, patient organizations can also help patients navigate digital health information [18]. According to the study by Kor et al. [19], chronic disease patients most often obtained online information related to COVID-19 from social media and search engines. At the same time, the large amount of information on social media can be confusing, especially for the elderly [20]. This means that patient digital health literacy is becoming a cornerstone of their search for reliable and relevant health information on the Internet [19].

Patient organizations can become an important support agent for chronic disease patients in the process of obtaining health information related to COVID-19, thus promoting their health literacy. However, it is important to note that patient organizations must critically evaluate the quality of their websites and the reliability of the information they contain [21].

The second area of impact was a change in internal and external communication modes in patient organizations, specifically the transition from face-to-face communication to distance communication. Diverse digital communication channels (patient organization websites; social media; video conferencing platforms (Zoom, Microsoft Teams, Skype); messaging apps (WhatsApp, Messenger)) were used for routine interaction with patients, caregivers, colleagues, and collaboration partners. A similar trend was observed in other studies and reports [4, 5, 15]. On the one hand, such digitalization led to some benefits (for example, saving financial and timely resources on business trips and face-to-face meetings or, in terms of information, reaching patients faster and more efficiently). However, the digitalization of access to information poses risks of inequality, mainly due to patients' limited digital literacy and limited access to technology. As a result, information can become unevenly available in different groups of patients. This raised concerns about the access to information in the pandemic period. This means that at a time when digital communication is becoming the 'new normal' [22], patient organizations must think about compensation mechanisms for access to information for patients who, for various reasons, are limited in accessing and using digital information.

Third, the chairpersons of the patient organizations reported a variety of challenges in continuing the routine management of the organizations in the context of COVID-19. Due to the instability and volatility of the overall situation during the COVID-19 pandemic, successive relevant changes and their planning and implementation are difficult. Therefore, traditional organizational change strategies must be adapted to the current conditions of the pandemic [23], in this case, adapting them to the functionality of patient organizations. In our study, the ability of chairpersons to adapt to the new needs of patients and to look for alternative solutions to continue to provide patient support and represent their interests was needed. Management theories suggest that, when changes are initiated in an organizational operation, managers should assess the current situation, purposefully expand knowledge, and take the lead in implementing changes [24, 25]. To ensure the continuity of the organization in a pandemic, the chairperson of the organization needs to know how to take different alternatives to actions and creative solutions [26]. For example, ensuring the digitalization process, the acquisition of new knowledge, the introduction of digital technologies, and the organization of work remotely can help adapt to the pandemic crisis [27]. The experts in our study also highlighted the importance of information exchange between different organizations by sharing good practices. Building and strengthening effective external partnerships is one of the key strategies to support organizations in times of crisis [26] and is essential to provide both informational and practical support.

Fourth, some patient organizations experienced financial instability due to a decrease in public and private funding. It revealed the financial vulnerability of the patient organizations. Although financial difficulties existed before COVID-19, they became more visible in the context of the pandemic and, in some cases, even threatened the functioning of the patient organization. The chairpersons concluded that a special support program is needed to ensure the sustainability of patient organizations were identified in similar articles [4, 5, 15]. Researchers also point to a confrontation between the growing needs of patients, the increased workload of patient organizations, and the reduced financial funding [4]. In our study, the chairpersons reported that more human resources were needed to provide services to patients whose needs for support and information have increased significantly and not all patient organizations were able to organize human resources promptly.

5 Limitations

This study has some limitations. First, the study included only the experiences provided by the chairpersons of patient organizations. The perspective of other employees, patients, and caregivers was not taken into account. Second, all participants who participated in the study were volunteers. It is possible that participation or non-participation in the study was influenced by some circumstances (e.g., personal qualities (extroversion, communicability, and research orientation, accessibility to digital devices, etc.). Third, we collected data between September 2020 and January 2021and asked the chairpersons about the experience of the first phase of COVID-19 (Spring-Autumn 2020) when the situation in Latvia was very changeable. The dynamics of the situation may have made it difficult for some respondents to recall the events and their sequence in detail.

6 Conclusions

Patient organizations were at the forefront of the fight against the COVID-19 pandemic, providing support to the patient groups they represent. The COVID-19 crisis put great pressure on the resources of patient organizations and exposed many challenges imposed by the pandemic. In the future, more coordinated action and additional support are needed for patient organizations that work in crises.

Funding:

This work was supported by the National Research Program to lessen the effects of COVID-19 (Latvia) (project number VPP-COVID-2020/1-0011).

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