Patient Organizations' Digital Adaptations to the COVID-19 Pandemic: A Scoping Review

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Submitted to: Journal of Medical Internet Research
on: March 19, 2024

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Abstract

Background: Patient organizations (POs) play a crucial role in supporting individuals with health conditions. Their activities range from counseling to support groups to advocacy. The COVID-19 pandemic and its related public health measures have prompted rapid digital transformation efforts across multiple sectors, including healthcare.

Objective: The objective of this scoping review was to explore how POs digitally adapted to the pandemic-related circumstances, focusing on aspects such as the technologies used, positive outcomes, and challenges encountered.

Methods: This scoping review followed the JBI Scoping Review Methodology and adhered to the PRISMA-ScR reporting guidelines. A systematic search of PubMed, the Web of Science Core Collection, and the WHO COVID-19 database, supplemented by a citation search approach, was conducted. Publications were eligible if they addressed pandemic-related digitalization efforts of POs, defined as nonprofit organizations with a focus on health-related support. A two-step screening process was used to identify relevant literature.

Results: The search and its subsequent update yielded 2,212 records, with a total of 13 articles included in this review. These articles revealed a range of PO services that were digitally adapted during the pandemic, with group-based support activities, including support groups, most commonly reported (n=9). While digital formats often increased accessibility and broke down pre-existing barriers, they also created new challenges, particularly for individuals who lacked digital skills or resources. Further findings suggest that online delivery of group activities preserved essential interpersonal aspects, as well as a preference among some participants to continue digital group activities, suggesting the potential for sustainability of digital options.

Conclusions: The rapid digitalization efforts of POs during the pandemic highlight their adaptability and the potential of digital technologies to improve support services. Future digitalization strategies should focus, among other things, on promoting digital literacy to ensure accessibility and inclusiveness of digital services. However, the long-term sustainability of these adaptations and their impact on POs remain areas for further research.

(JMIR Preprints 19/03/2024:58566)
DOI: https://doi.org/10.2196/preprints.58566

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Review

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Background: Patient organizations (POs) play a crucial role in supporting individuals with health conditions. Their activities range from counseling to support groups to advocacy. The COVID-19 pandemic and its related public health measures have prompted rapid digital transformation efforts across multiple sectors, including healthcare.
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Conclusions: The rapid digitalization efforts of POs during the pandemic highlight their adaptability and the potential of digital technologies to improve support services. Future digitalization strategies should focus, among other things, on promoting digital literacy to ensure accessibility and inclusiveness of digital services. However, the long-term sustainability of these adaptations and their impact on POs remain areas for further research.

Keywords
Patient organization, COVID-19, digital adaptation, digitalization, scoping review

Background

Patient organizations (POs)[1] provide crucial support to individuals affected by health conditions, such as chronic diseases, and their relatives. Their support activities can range from direct services, such as individual counseling, support groups, and health education programs, to more indirect forms of support, such as advocacy in research or policymaking [1–5]. In addition to differences in their primary purpose and scope of activities, POs also differ in organizational characteristics such as their

[1] For the sake of clarity and readability, we use the term "patient organization" exclusively in this review, rather than alternative terms such as "patient association," "patient advocacy organization," "self-help organization," "voluntary health agency." It is important to note, however, that we have considered such potential synonyms throughout this review.

internal structures and the financial resources available to them, adding to the complexity of the PO landscape. In Germany, for instance, Kofahl et al. [3] found that almost half of the POs (47%) are run entirely by volunteers, while others have the capacity to employ full-time staff, ranging from one employee (17%) to five or more (15%). Membership sizes also vary widely, from a few individuals to more than 50,000 [3]. In the United States, Rose et al. [4] found considerable financial variation among POs. While some highly professionalized POs reported annual revenues exceeding $ 1 million, the median revenue for American organizations was $299,140, suggesting that many operate on a smaller financial scale. This marked diversity among POs may contribute to the lack of a universal definition, with terms such as 'patient association', 'patient advocacy organization', and 'self-help organization' being used interchangeably [2–4]. A unifying characteristic, however, is their commitment to supporting their respective target groups and to maintaining a non-profit status [4,5].

However, the onset of the COVID-19 pandemic drastically changed the circumstances of interpersonal interactions, often making it impossible to provide any kind of face-to-face service, as governments worldwide enacted public health protection measures that often included restrictions on mobility and direct contact [6]. These policies have triggered rapid digital transformations in various social domains, including work, education, business, and healthcare [7–9]. In healthcare, for example, several recent reviews have demonstrated a rapid and notable increase in the use and adoption of telemedicine and e-health applications [10–13].

Given the widespread impact of the pandemic and the resulting surge in the use of digital technologies, it is reasonable to assume that POs underwent similar digital adaptation efforts, changing their operational approaches and support delivery. The extent and effectiveness of these pandemic-induced digital adaptations likely varied across POs, reflecting not only the diversity described above, but also varying levels of pre-pandemic digitalization. Before the pandemic, research indicated that the level of digitalization among POs varied widely. While many relied primarily on basic digital communication tools such as websites, email, and social media, others embraced advanced technologies and developed interactive platforms, mobile applications, or electronic patient databases to enhance the use of digital patient data for research [14–16]. These differences in digitalization levels may be linked to the organizational characteristics described above, as well as additional factors such as the digital literacy of PO leadership and members and their demographic profile [14].

However, despite the significant role of POs as supporters and advocates, we found no comprehensive reviews synthesizing the existing research literature on their digitalization efforts during the COVID-19 pandemic. While several reviews have addressed the use of digital technologies in healthcare during the pandemic [17–21], the specific focus on POs remains conspicuously absent. This gap leads us to our central research question:

How have POs adapted digitally in response to the COVID-19 pandemic?[2]

To specifically address certain aspects of these adaptation activities, we applied the following sub-questions[3]: What digital technologies were adopted by POs in response to the pandemic? What were the positive outcomes, challenges, and facilitating factors associated with these digital transformation efforts? Our findings on these matters may also eventually provide valuable insights for POs and similar organizations to guide future digitalization strategies and improve digital readiness for such unprecedented events.

[2] Deviation from protocol: The main research question was further refined prior to conducting the systematic search to emphasize the goal of this review to provide insight into how POs digitally responded to pandemic-related circumstances. The original draft, as presented in our protocol, is worded more broadly, suggesting the exploration of the overall impact of the pandemic on the digitalization within POs. Such an overall impact might be more of a long-term effect that should be addressed in a future review with the appropriate temporal distance to the pandemic.

[3] Deviation from protocol: Sub-questions were further refined prior to the systematic search without changing their initial meaning.

Methods

This scoping review is based on the methodological guidance developed by the JBI Scoping Review Methodology Group [22]. In regard to reporting, we adhered to PRISMA-ScR [23].

Protocol and Registration

A protocol was developed and registered with the Open Science Framework prior to the conduct of this review [24]. Given the iterative nature of scoping reviews, deviations from the initial protocol are generally possible [22,25]. Any deviations are documented as footnotes in the subsequent sections for transparency and justification.

Eligibility Criteria

We established a set of eligibility criteria to systematically identify relevant literature (see Table 1). These criteria can be divided into two main types: formal aspects (criteria 1 to 5) and content-related aspects (criteria 6 and 7).

Regarding the latter, they correspond to the PCC (population, concept, context) elements of our research question, a mnemonic often used to construct the title and main research questions of a scoping review [22,25] (see Multimedia Appendix 1). Accordingly, articles were considered eligible if they addressed digitalization efforts initiated by patient organizations (POs) during and in response to the COVID-19 pandemic. We defined these processes as the adoption, development, or use of digital technologies for activities previously conducted in-person or as the upscaling of existing digital services. In order to provide a comprehensive overview in our scoping review, it was essential to recognize the aforementioned structural and functional variations of POs when defining our inclusion criteria. Therefore, we adopted a broader definition of such organizations, focusing on common characteristics, particularly their nonprofit status and commitment to supporting individuals affected by specific health conditions. This may include direct support, like counseling or peer support, as well as indirect support, such as advocacy or research funding. Articles that addressed the digitalization of peer support groups were also included if such groups were associated with a PO. We did not consider government agencies, faith-based groups, or academic institutions eligible, as they differ significantly from our applied definition of PO. This distinction ensures methodological consistency and precision and recognizes the diverse international landscape of such entities.

Regarding the former (formal inclusion criteria), these included article type, date, and language. We used these criteria to establish a consistent, transparent, and reproducible selection process. Acknowledging that the scope of published literature has not been previously summarized, we adopted a broad approach for certain criteria to ensure comprehensive coverage. For instance, we did not impose limitations on the type of article or study design.

Table 1. Inclusion criteria.

1	The full text of the article is available.
2	The article is published in English or German.
3	The article was published after November 30th, 2019.
4	The article is not a duplicate publication.
5	All types of articles published in a scientific journal, regardless of study design or methodological approach, are eligible. *Exception: Study protocols and conference proceedings are not eligible, as we do not consider them to be full publications due to the preliminary or limited information they contain.*
6	**Concept**[4]

	Eligible articles must report on digitalization efforts or initiatives within the PO that have been initiated, accelerated, or expanded to adapt to the COVID-19 pandemic, which may include the adoption, development, or use of any digital technology for PO activities or services.
7	**Context**[5] Eligible articles must describe the efforts and initiatives of non-profit POs that provide direct or indirect support to individuals affected by health conditions. Support groups will be included if they are affiliated with a PO. The geographic location of the POs is not a consideration for eligibility.

Information Sources and Search Strategy

To ensure that our systematic literature search was comprehensive, we selected the bibliographic databases PubMed, Web of Science Core Collection, and the WHO COVID-19 Research Database as sources of information. The search strategy was first developed for PubMed and then adapted for the other databases. It consists of three thematic search blocks, each containing different synonymous free-text terms and, if available in the databases, corresponding controlled vocabulary terms: 1) patient organizations, 2) digitalization and digital technologies, and 3) the COVID-19 pandemic. The creation of the third search block was based on PubMed's general COVID-19 article filter 'LitCovid' [26]. Where possible, a publication language restriction was included in the search strings. A publication date restriction was not included, as this period naturally coincides with the onset of the pandemic (see Multimedia Appendix 1 for the search strings). The initial search was performed on November 10, 2022, and updated on November 8, 2023. Citavi 6 was used for duplicate elimination and literature management. To further increase the comprehensiveness of our search and to identify additional eligible articles, a citation search was conducted.

Selection Process

To systematically identify all relevant articles, we adopted a two-step selection process. First, SW and CJ independently screened titles and abstracts of all articles for eligibility based on our inclusion criteria (see Table 1). When both reviewers considered an article potentially eligible, it was forwarded to the full-text screening for further evaluation. Those that did not meet the eligibility criteria were excluded, and conflicting assessments were discussed. If a consensus could not be reached, the article was also forwarded to full-text screening. Full texts of all preselected articles were then obtained and independently reviewed by SW and JL for final inclusion according to our inclusion criteria (see Table 1). Conflicting assessments were discussed to reach a consensus. We did not involve a third independent reviewer in the selection process, as all conflicts could be resolved at this stage. The screening process during the search update was also carried out using the two-stage selection approach and was performed by SW and JL. We used Rayyan to conduct the selection process for both the initial search and the update search. The citation search was also performed independently by two reviewers (SW, CJ). It involved screening the reference lists of the included articles and searching Google Scholar for articles that cited them. The two-step selection process was followed. The citation search approach was also applied to articles identified during the update of the systematic search, which was conducted by SW and JL.

[4] Deviation from protocol: The wording of eligibility criterion 6 was further refined prior to the systematic search without changing its initial meaning.

[5] Deviation from protocol: The wording of eligibility criterion 7 was further refined prior to the systematic search without changing its initial meaning. It was also decided to exclude COVID-19-specific online support groups from the review to maintain thematic consistency. The focus is on the adaptive responses of established patient organizations and support groups, rather than services that are newly established in response to COVID-19-specific needs, such as groups for long COVID patients. It was recognized that COVID-19-specific services represent a distinct area of research that may need to be addressed in other reviews.

Quality Assessment

A critical appraisal of the methodological quality of the included articles was not performed. This is in line with the standard approach for scoping reviews to provide an overview of the existing sources of evidence on a particular topic, regardless of their methodological quality [25].

Data Charting

To extract the relevant data from each included article, we developed a standardized table, aligned with the PCC elements of our primary research question and the additional sub-questions. The extracted data included:

- bibliographic information (e.g., first author, title, year of publication),
- methodological information (e.g., study design/methodological approach),
- information on the PO/s (e.g., type of entity, its specific indication),
- information on the digital adaptations activities (e.g., types of digital technologies implemented, positive outcomes and facilitating factors identified, challenges encountered).

Given the potential diversity in reporting measures, styles, and depth, and to maintain transparency and coherence, we focused our extraction on information explicitly linked to digital adaptation activities. This included aspects like the transformation of in-person services, members' experiences in online support group activities, or the upscaling of existing online services. If a link to digital adaptation efforts was not clearly identifiable, we excluded such information from the data extraction. For example, a study reporting a lack of funding as a major challenge for POs during the pandemic was not included unless the challenge was related to funding for such digitalization measures. SW and JL collaboratively extracted the data, with each handling half of the included articles, to ensure consistency and accuracy in the process.

Analysis and Data Synthesis

Following the data charting, we condensed each extracted text-based information and assigned thematic codes inductively. We then grouped them under broader categories that were applied throughout the data extraction of all included articles for a structured and comprehensive analysis. In addition to the data analysis, we narratively synthesized the findings with the aim of 1) highlighting similarities and differences among the included articles, and 2) describing potential trends using a slightly quantitative approach by presenting the frequency of reporting (e.g., regarding the digital technologies used or services that have been digitized). First, we summarized the characteristics of the included articles. Next, we synthesized information about the POs, including their types. Finally, we described the characteristics of the digital adaptation efforts as reported in the articles.

Results

Search and Selection of Articles

The systematic search in bibliographic databases, along with its update, yielded a total of 2,212 results after the removal of duplicates. Of these, 10 references met the eligibility criteria and were included in our review. The citation search yielded 3 additional eligible references. Thus, after completion of all screening steps, 13 articles were finally included. Figure 1 shows the selection process during the initial search using a PRISMA flowchart. The search update is illustrated in Multimedia Appendix 2.

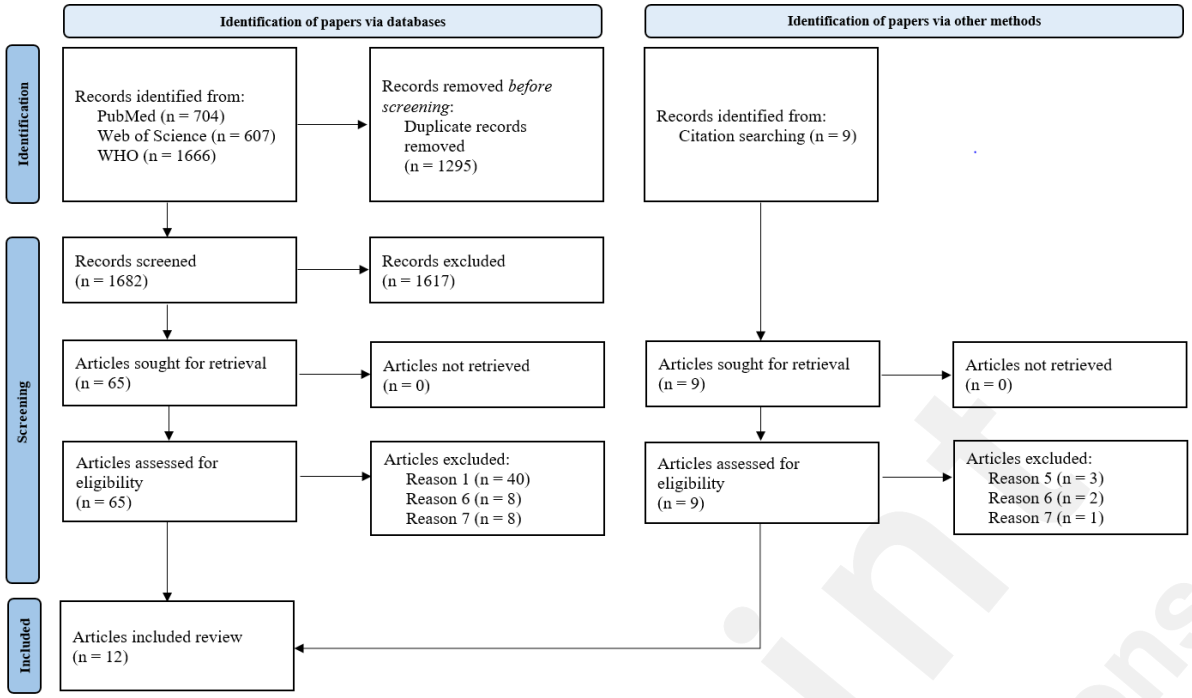

Figure 1. PRISMA 2020 flow diagram of the selection process during the initial search.

Characteristics of Included Articles

Of the 13 included references, 9 were original research articles. Of these, most were empirical studies employing a qualitative (n=4) or mixed methods approach (n=4). Of the remaining 4 articles, 1 was based on a survey but was published as a data note due to its unexpectedly small sample size [27]. The other 3 articles can be broadly categorized as experience reports, as they aimed to describe practical examples or lessons learned regarding digital transformation without collecting data in this context [28–30].

Most of the included articles were published within the first two years of the COVID-19 pandemic. Of the 3 included articles published in 2023, Bouey et al. [31] was initially identified as a preprint, flagged as relevant, and included when it was fully published. Constantini et al. [32] was identified through the search update.

The majority of the included articles (n=8) reported receiving financial support from a patient organization (PO) or indicated varying degrees of involvement by representatives of a PO [28–31,33–35], or an umbrella organization of POs [36]. Table 2 presents the objectives of the included articles, while

Error: Reference source not found outlines their general characteristics. See also Multimedia Appendix 3.

Table 2. Objectives of included articles (N=13).

Reference	Objective
Beck et al. [37]	Evaluate SMART Recovery Australia's scale-up of online support groups during the COVID-19 pandemic.
Bergmans et al. [28]	Present lessons learned from transitioning the Skills for Safer Living (SfSL) intervention to a virtual format.
Bouey et al. [31]	Explore challenges Chinese POs faced during the first COVID-19 lockdown and how they responded.
Chung et al. [36]	Examine the impact of the pandemic on rare disease POs in the Asia-Pacific region.

Reference	Objective
Constantini et al. [32]	Compare the experiences of members of support groups that have moved to an online format with general findings of the literature on online groups.
Kelly et al. [29]	Discuss the global impact of COVID-19 on SMART Recovery International with facilitators from different regions.
Lamont et al. [35]	Explore stroke survivors' perceptions of social support and shared identity within stroke groups during COVID-19 and its impact on psychosocial health.
Marks et al. [34]	Investigate the effectiveness and experiences of participants in online tinnitus support groups and educational webinars implemented during COVID-19.
McMullan et al. [27]	Examine the impact of the pandemic on rare disease POs in Ireland and the UK.
Nemeth Blažić et al. [30]	Describe, among other things, the digitalization of a PO's voluntary HIV, HCV, and STI counseling and testing services during the pandemic.
Penfold and Ogden [38]	Explore Gamblers Anonymous members' experiences with online meetings during the pandemic to understand the effectiveness and support provided compared to in-person sessions.
Seckam and Hallingberg [33]	Examine stroke survivors' experiences with the transition from live to virtual choir sessions during COVID-19.
Senreich et al. [39]	Explore 12-Step program attendees' experiences with in-person groups transitioning to online meetings.

Table 3. Characteristics of included articles (N=13).

Characteristics	n (%)	References
Publication year		
2021	5 (38)	[27–29,33,36]
2022	5 (38)	[30,34,35,38,39]
2023	3 (23)	[31,32,37]
Article type		
Data note	1 (8)	[27]
Report	3 (23)	[28–30]
Research article	9 (69)	[31–39]
Methodological approach		
Mixed-methods	4 (31)	[31,32,36,37]
Non-empirical	3 (23)	[28–30]
Qualitative	4 (31)	[33,34,38,39]
Quantitative	2 (15)	[27,35]
PO involvement		
Funding by PO	1 (8)	[35]
Involvement of PO representative(s)	5 (38)	[28–31,33]
Involvement of representative(s) from an umbrella organization of POs	1 (8)	[36]
PO representative involvement and PO funding	1 (8)	[34]

Characteristics of POs

The majority of the included articles (n=8) addressed POs that are involved in a broader range of activities, including direct support services, advocacy, or research participation [27,28,30,31,33–36]. Meanwhile, 5 articles reported on POs, such as SMART Recovery, that primarily provide peer support groups [29,32,37–39]. Of all included articles, 8 specifically explored the digital adaptation

of POs' group-based support activities without addressing other organizational elements [28,29,32,33,35,37–39]. Moreover, a focus on well-established POs such as SMART Recovery [29,37], the Stroke Association [33,35], or the Canadian Mental Health Association [28] was predominant among the included articles.

The majority of included articles focused on POs within specific countries. Most articles (n=8) reported on individual POs operating within a single country [28,30,32–35,37,38], while 2 explored multiple POs within the same national context [31,39]. In addition, 2 articles expanded its scope to include POs in a transnational region [27,36], and another provided an international overview by focusing on SMART Recovery International and its network of global affiliates [29]. Among all the articles, POs based in the UK were the most commonly reported on (n=5).

In terms of the health conditions addressed by the POs, addictive behaviors were the most common (n=4), followed by stroke (n=2), HIV/STI (n=2), and rare diseases (n=2). Table 4 provides an overview of aspects related to the PO settings, as reported in the included articles. See also Multimedia Appendix 3.

Table 4. Characteristics of POs as reported in the included articles (N=13).

Characteristics	n (%)	References
Indication		
Addictive behaviors	4 (31)	[29,37–39]
Dementia	1 (8)	[32]
HIVand other STIs	2 (15)	[30,31]
Mental health	1 (8)	[28]
Rare diseases	2 (15)	[27,36]
Stroke	2 (15)	[33,35]
Tinnitus	1 (8)	[34]
Geographic location		
Australia	2 (15)	[36,37]
Austria	1 (8)	[32]
Canada	1 (8)	[28]
China	2 (15)	[31,36]
Croatia	1 (8)	[30]
Hong Kong	1 (8)	[36]
India	1 (8)	[36]
Ireland	1 (8)	[27]
Japan	1 (8)	[36]
Malaysia	1 (8)	[36]
New Zealand	1 (8)	[36]
Philippines	1 (8)	[36]
Singapore	1 (8)	[36]
Taiwan	1 (8)	[36]
Transnational (PO[a] with affiliations in Australia, Brazil, Denmark, Hong Kong, Ireland, Malaysia, Spain, UK, USA)	1 (8)	[29]
UK	5 (38)	[27,33–35,38]
USA	1 (8)	[39]
Digitally adapted PO activities and services during COVID-19		
Group-based support activities	9 (69)	[28,29,32–35,37–39]
Communication and counseling	4 (31)	[27,30,31,36]
Information provision and educational	3 (23)	[27,34,36]

activities		
Operational activities	2 (15)	[27,36]

[a] SMART Recovery International

POs' Digital Adaptations to the COVID-19 Pandemic

Among the articles reviewed, digital adaptations of various PO activities in response to COVID-19 related public health measures were described. Most (n=9) focused on the digitalization of a specific PO activity [28–30,32,33,35,37–39], while 4 explored the digital transformation of multiple [27,31,34,36]. These digitally adapted services and activities can be broadly categorized into three main themes: group-based support activities, communication and counseling, as well as information provision and educational activities (see Figure 2).

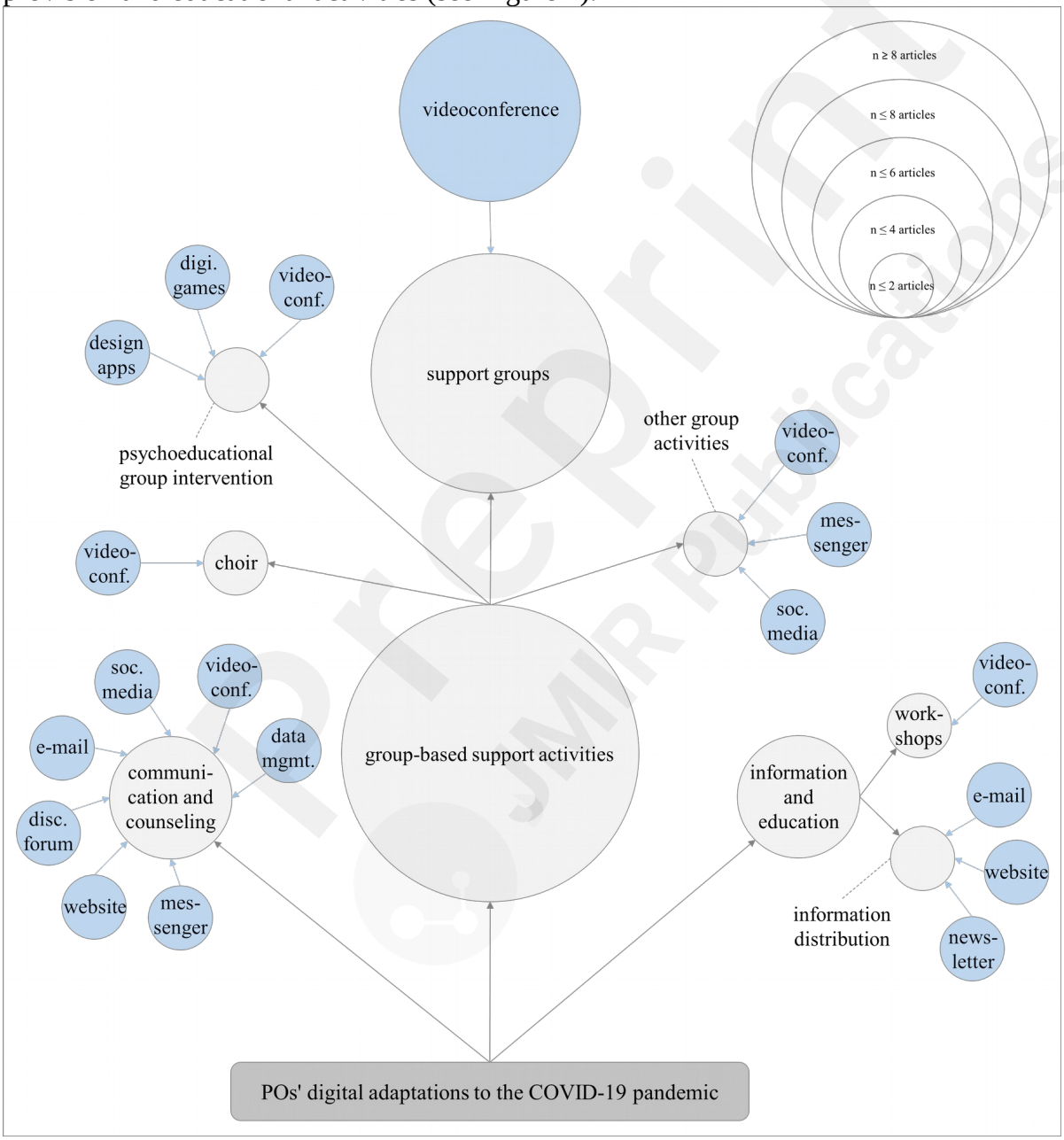

Figure 2. PO activities and services digitally adapted during the COVID-19 pandemic (grey bubbles) and the technologies used (blue bubbles).

Group-Based Support Activities

The digitalization of group-based support activities is the most frequently reported aspect (n=9), with

peer support groups discussed in 7 articles [29,32,34,35,37–39]. This includes both the novel transformation from face-to-face to online groups [32,34,38,39] as well as the significant expansion of existing online groups that were previously less common and mainly held in conjunction with face-to-face meetings [34]. Kelly et al. [29] discussed the response of SMART Recovery International, a global community of peer support groups for addictive behaviors. In some countries, like the US, this involved notably increasing the number of existing online support groups to compensate for the discontinuation of in-person groups, while in others, such as Denmark, online groups were established for the first time. Lamont et al. [35] described various digital communication methods used by facilitators and members of stroke groups of the Stroke Association (UK) to maintain engagement. Originally, peer support, creative arts and stroke cafés were among the activities of these groups. However, the extent of digital transition remains ambiguous as the original core activities were not necessarily directly adapted, with Lamont et al. [35] reporting that digital tools were primarily used to keep in touch. Other POs' group activities that were digitally transformed during the pandemic include a choir [33] and a psychoeducational group intervention [28].

In terms of digital technologies used, video conferencing software, such as Zoom, was specifically mentioned in 7 articles, making it the most commonly used tool in the process of digital adaptation [28,32–35,37,38]. The remaining 2 articles did not specify the technology used for such online groups [29,39]. See Multimedia Appendix 4, Table S 1, for further details.

Positive Outcomes

The most commonly reported benefits of digitally adapting group-based support activities during the pandemic were preserving interpersonal dynamics and increasing accessibility (refer to Multimedia Appendix 4, Table 2, for details on other positive outcomes).

Interpersonal Dynamics

Of the 9 articles addressing group-based support activities, 7 reported that the interpersonal nature of such activities was successfully preserved in online formats [28,32–35,37]. For instance, Seckam and Hallingberg [33] observed that participants felt inspired by the meetings with their fellow members and experienced a sense of belonging in the digital environment, which helped reduce feelings of social isolation. Similarly, Marks et al. [34] reported that participants felt less isolated, experienced social or emotional connections with other group members, and shared information and stories within the online environment. Penfold and Ogden [38] also observed social comparison as well as interpersonal dynamics such as social affirmation, solidarity, and feelings of togetherness in online meetings. Both conclude that key elements of group meetings have been preserved during the digital transition [34,38]. Lamont et al. [35] observed a high level of social identification of members with their group during the pandemic, resulting in more positive psychosocial outcomes. The authors attributed this to groups maintaining collective and individual interactions, primarily through online communication tools such as email, video calls, and text messages, as well as non-online means such as phone calls.

Accessibility

Several articles (n=5) referred to the impact of the digital transition on the accessibility of group-based support activities. For instance, 3 articles reported improved access for people who were previously unable to participate in person due to barriers related to physical or mental health conditions, work, or financial resources [28,34,39]. By moving to online formats, some POs also expanded the accessibility of their digital group activities nationally or even internationally [29,34,38,39]. This newly gained accessibility was viewed positively by some participants. Penfold and Ogden [38] highlighted that participants appreciated being able to choose from a wider range of meetings, and Senreich et al. [39] observed that the increased diversity of participants – due to the broader access – was positively perceived.

Challenges and Barriers

At the same time, this shift to online formats also introduced several challenges to the delivery of group-based support activities. Access barriers, particularly for those individuals lacking digital resources or skills, were most commonly reported [33–35,39]. Furthermore, the accessibility of group activities was sometimes negatively affected by technological difficulties, such as poor Internet connections [32,37].

In contrast to the finding that maintaining the dynamics of group interactions was identified as a benefit of online formats, 3 articles reported that some group members were less satisfied with such formats, particularly in terms of interpersonal aspects, such as feeling rather disconnected from the group and lacking a sense of community [34,38,39]. Furthermore, the absence of informal conversations and interactions typically surrounding in-person meetings was viewed negatively [39], posing challenges in developing relationships within the groups for some [34]. For more details, see Multimedia Appendix 4, Table S 3.

Facilitating Factors

From the perspective of an internationally operating PO, Kelly et al. [29] reported on the challenges SMART Recovery International faced in digitally transforming support groups in countries without previously established online groups. Here, the digital environment had to be created from scratch and facilitators had to be trained respectively. However, the authors also mentioned that collaborating transnationally and sharing experiences with SMART Recovery affiliates in countries with pre-existing online groups proved to be beneficial. Participants' prior experience with digital technologies [32,33], the presence of experienced group facilitators [32,34], and government funding [29,37] also had a positive impact on the digital transformation of group activities. See Multimedia Appendix 4, Table S 4, for more details.

Communication and Counseling

Chung et al. [36] and McMullan et al. [27], based on their surveys with representatives of rare disease POs, reported that the majority of these participating organizations used various forms of online communication to maintain contact with their members and continue to provide support during the pandemic. This included enabling interactions via video calls, social media, and discussion forums.

Additionally, Chung et al. [36] described the digitalization of counseling services that were previously offered in person. Bouey et al. [31] and Nemeth Blažić et al. [30] also discussed this transition, focusing on POs that provide support and care regarding STIs, particularly HIV/AIDS, where counseling is an integral part of their HIV prevention and testing activities. Various digital technologies were used to maintain support through counseling during the pandemic, such as videoconferencing software, email, and social media.

Chung et al. [36] reported that relying on online communication tools during the pandemic posed challenges to adequately supporting all members, as not all had access to the necessary digital technologies or were skilled enough to use them.

We could not identify any information on facilitating factors specifically associated with the digital transformation of POs' of communication and counseling services (Multimedia Appendix 5, Tables S 1-4).

Information Provision and Educational Activities

The digital adaptation of POs' information provision and educational activities is addressed in 3 of the included articles [27,34,36]. Marks et al. [34] described the establishment of online educational workshops, while McMullan et al. [27] briefly mentioned the implementation of weekly webinars and the distribution of information updates and newsletters. Similarly, Chung et al. [36] reported the

use of newsletters, along with the use of POs' websites, as methods of disseminating information to members during the pandemic.

Marks et al. [34] observed that participants in online educational workshops experienced social support and a sense of collectivity, echoing findings from digital group-based support activities. They also deduced from their qualitative interview data that professional facilitation and moderation created a positive learning environment where participants felt motivated and comfortable to engage. Attributes specific to the digital format, such as the ease of information sharing via chat, enhanced the learning experience. However, Marks et al. [34] also described challenges associated with the use of digital technology for some participants. Further details are provided in Multimedia Appendix 5, Table S 1-4.

Operational Activities

Chung et al. [36] and McMullan et al. [27] also addressed how POs have digitally transformed rather operational aspects . McMullan et al. [27] specifically mentioned the transition of committee meetings to videoconferencing formats. Chung et al. [36] also noted the digitalization of meetings, though they did not specify the types, and further addressed the broader digitalization of organizational operations as an adaptive response to the pandemic. Their survey of directors and representatives of rare disease POs in the Asia-Pacific region revealed that the 'digitalization of operation' was most frequently stated as the predominant factor contributing to the perceived success of POs during the pandemic. However, the survey also showed that the actual success of these digital adaptation efforts varied by geographic region. For example, all 15 Australian organizations reported successful digital adaptation of their operations, while none of the 18 participating POs from Hong Kong were able to digitally adapt. The authors hypothesize that this disparity may be due to differences in the availability of the necessary digital infrastructure. See Multimedia Appendix 5, Tables S 1-4, for more details.

Discussion

Based on the results of our systematic literature search, this review provides a comprehensive overview of how various patient organizations (POs) have adapted their services and operations to digital formats in response to pandemic-related circumstances. It covers a wide range of organizational types, health-related indications, and geographic areas, highlighting the broad impact of the pandemic.

Principle Findings on POs' Digital Adaptations

Our analysis reveals that the COVID-19 pandemic prompted various digital adaptation responses from POs. It led to the adoption of new digital solutions or, in some cases, the significant expansion of existing digital services to maintain essential activities under pandemic conditions and to meet support needs. All articles reported largely successful digital adaptations by POs and their associated support groups, ensuring the continuation of their services in the midst of the pandemic. This is consistent with broader trends in the health sector, where rapid digital transitions have played a critical role in maintaining service delivery [13,17,18,20,21].

As all included articles focus on the immediate impact of the pandemic and the rapid adoption of digital solutions, it is not possible to reach definitive conclusions about the long-term impact of the pandemic on digitalization within these organizations or its sustainability. However, our findings from 4 articles suggest a preference among some participants for the continuation of digital group activities [32,34,37,39]. This observation allows for deductive considerations regarding the future role of of digital services, specifically, that digital options might be preserved alongside the resumption of in-person meetings, particularly where digital experiences have been positive. Therefore, future research could explore the long-term implications of pandemic-induced digital

transformations within these POs.
Another notable finding is that the digital transformation of group-based support activities is the most frequently and extensively reported adaptation response in our sample (n=9). This trend may be related to the fact that providing peer support, such as through support groups, is a core task of many POs [2,4,5]. The pressing need to digitize these services during the pandemic, which was likely a priority for organizations to continue providing support, may explain the extensive reporting of this transition.

Digital Technologies

The predominant use of videoconferencing software during the pandemic-driven digitalization is consistent with trends observed in various sectors, such as higher education [40] and healthcare [17]. This widespread adoption may be related to the nature of these tools, which enable audiovisual communication and are therefore closest to a face-to-face interaction. Consequently, videoconferencing offers a more comprehensive mode of interaction, potentially making it a more appealing alternative for social interaction than purely speech- or text-based forms. Prior to conducting our review, we had considered the possibility that POs might develop specific digital solutions, most likely in collaboration with software developers, to better customize their services and meet the needs of their members. However, our findings did not indicate such developments. This may be due to the rapid and urgent nature of the pandemic-related digital adaptations, which likely made the development of specialized technologies impractical at the time. In addition, the relatively high cost may have been a limiting factor.

Positive Outcomes, Challenges and Facilitating Factors

The majority of articles addressing group activities reported that participants in online groups experienced interpersonal aspects similar to those in face-to-face groups, e.g., a sense of togetherness. This observation supports similar trends identified in general findings on the conduct of various online support group formats, that have emerged independently of the COVID-19 pandemic [41–43]. Consequently, online groups may indeed serve as adequate alternatives to face-to-face group activities of POs. Another positive outcome highlighted in several articles is the increased accessibility that has resulted from digitizing group activities. This shift has effectively removed several pre-existing barriers, allowing participants to access meetings from anywhere. This has been particularly beneficial for individuals who are limited by financial or mobility constraints. This reported benefit of improved access through digital technologies is consistent with previous findings, both during [13,20] and outside of the pandemic period [41]. However, our review also shows that the shift to online formats has simultaneously created new barriers, particularly for those with limited digital literacy or resources. These challenges also appear to transcend the pandemic context, as evidenced by other findings on digital health in both pandemic [13,20] and non-pandemic settings [44,45]. This dichotomy points to the dual nature of digital formats, as they can both bridge and widen access gaps, and underscores the importance of nuanced consideration.
Regardless of the specific service or activity, we found that comparatively few factors were consistently reported as facilitators of the digital transformation. The beneficial impact of the presence of skilled facilitators on the smooth digital adaptation of support groups and educational workshops, as reported by Marks et al. [34] and Constantini et al. [32], is also highlighted in a review not specifically related to the pandemic [45], making this a potentially relevant general recommendation for the future delivery of online activities. From a more general perspective not focused on group activities, Chung et al. [36] identified pre-existing digital resources and experience in delivering online services and activities as important facilitators of digital adaptation.
In conclusion, when establishing any kind of digital services within POs, it is likely to be advantageous to promote digital literacy among members and participants and to create solutions for

those without access to digital technologies, as well as to be digitally equipped and experienced as an organization.

Ethical Issues

In the context of digital transformation in healthcare, for example, ethical implications such as privacy and justice as well as related issues are being discussed [46]. With this in mind, our review also sought to explore if and how POs addressed ethical concerns during the rapid digitalization efforts spurred by the pandemic. Notably, only Seckam and Hallingberg [33] explicitly addressed ethical considerations, specifically noting the unintentional exclusion of some members from virtual choral activities due to digital literacy gaps or lack of necessary technology. While other articles [33–35,39] also reported this challenge regarding the accessibility of online formats, they did not explicitly categorize it as an ethical issue. Bergmans et al. [28], Penfold and Ogden [38], and Senreich et al. [39] observed privacy concerns, although not explicitly as an ethical issue. These potential challenges regarding fair access and privacy align with those identified in the broader digital health landscape, where ethical guidance is suggested as an initial solution for such initiatives [46]. However, only Bergmans et al. [28] reported mitigating actions, like 'coaching' sessions to help participants navigate virtual format privacy settings. Other articles did not specify POs' approaches to these potential ethical challenges.

Limitations of Findings

Firstly, our analysis is based on a limited sample of publications, that may not fully represent the situation of all POs. Our search primarily yielded articles focusing on organizations in Europe (particularly. the UK) and therefore, our findings may not fully capture the global situation. Digital adaptations related to the pandemic may have varied significantly in countries not included in our sample. In addition, the majority of the articles focused on well-established organizations with the resources to actively support research. Of these, 7 articles included such funding or active collaboration with POs, so these factors may have influenced the scope of the available research on this topic. As a result, the experiences and perspectives of smaller, less financially equipped organizations may be underrepresented in our findings, despite representing a large proportion of POs in, for example, Germany or the United States [3,4]. Further, we found that despite the diverse activities of POs, the articles in this review did not address instances in which these organizations acted as advocates, which may include efforts to influence health policymaking, collaborate with other health care stakeholders, or engage in research. Consequently, it remains unclear whether these specific activities were also adapted to digital formats.

Having acknowledged these limitations, it is important to clarify our objective. The primary purpose of this review was not to generate generalizable findings or to provide a comprehensive picture of the global situation. Rather, our aim was to determine what literature has been published on the topic, describe individual findings, identify emerging trends, and highlight research gaps. In fact, the absence of articles addressing certain gaps identified in our review is more indicative of a lack of diversity in the context of the published literature. This may be due to factors such as POs lacking the necessary financial or human resources for research involvement, or possibly because engaging in research or publishing in academic journals is not a priority for some POs

Lastly, the quality of reporting within our sample varies, particularly in terms of depth. For example, most articles did not focus on the digital transformation process as such. This variation means that the amount of information we gathered and extracted varied. As a result, not all aspects of digital transformation were reported in each article, nor were they necessarily covered to the same extent.

Methodological Limitations

A challenge in developing our search strategy was the lack of consistent terminology and definitions

for POs. Hence, we used a sensitive approach to develop our search strategy, incorporating various synonyms to retrieve relevant literature. After the initial search and screening, we identified additional terms as potentially relevant, such as 'voluntary health agency'. The fact that adding these terms to the search strategy did not any yield additional relevant publications gives us further confidence that our search was sensitive.

Also, we employed a definition of POs that may reflect a rather Western perspective. Potentially, even broader inclusion criteria might have yielded more publications. However, this approach may have resulted in a sample with significant variation across organizations, making comparisons impossible.

Finally, we included only articles published in English or German to ensure feasibility. The overall search results in PubMed, for example, showed only a modest increase in search results (0.87%) when no language filter was applied and hence this language restriction appears to have been negligible.

Conclusion

Our findings on these rapid transitions can be taken as an indicator of the resilience and adaptability of these patient organizations (POs), and underscore the significant potential of digital technologies to enhance support services in such unprecedented times.

Based on the various aspects we identified in this review, potentially relevant recommendations for future PO digitalization strategies relate to promoting digital literacy among members and participants, creating solutions for those without access to digital technologies, and training PO staff to provide skilled and supportive delivery of online services.

Our findings also highlight several research gaps. For example, there seems to be a predominant focus in the literature on well-established organizations in Western countries. This may overlook the unique experiences of smaller, less well-funded POs or those in different geographical areas. In addition, the current literature does not provide insights into areas such as advocacy or research engagement and their digital adaptations, suggesting potential areas for further research. Furthermore, while our review highlights the immediate digital responses of POs to the pandemic, the long-term sustainability and impact of these adaptations remain unclear. Future research should explore these aspects to fully understand the long-term impact of the COVID-19 pandemic on POs.

Authors' contributions

SW: Developed the concept and methodological approach, wrote the protocol, performed literature screening, performed data extraction and data analysis, drafted and edited the manuscript.
MLD: Contributed to the conceptualization and development of the methodological approach, reviewed the manuscript, and served as project coordinator.
CJ: Contributed to the development of the search strategy and literature screening.
JL: Contributed to the conceptualization and development of the methodological approach, performed literature screening and data extraction, reviewed and edited the manuscript.

Conflict of Interests

None declared.

Funding

This scoping review was conducted as part of the PANDORA research project, funded by the German Federal Ministry of Education and Research (BMBF); research grant ID: 01GP2115B.

Abbreviations

BMBF: German Federal Ministry of Education and Research
HCV: Hepatitis C Virus
JBI: Joanna Briggs Institute
PO(s): Patient Organization(s)
PRISMA-ScR: Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews
SfSL: Skills for Safer Living
SMART: Self-Management and Recovery Training (in the context of SMART Recovery)
STI: Sexually Transmitted Infection
WHO: World Health Organization

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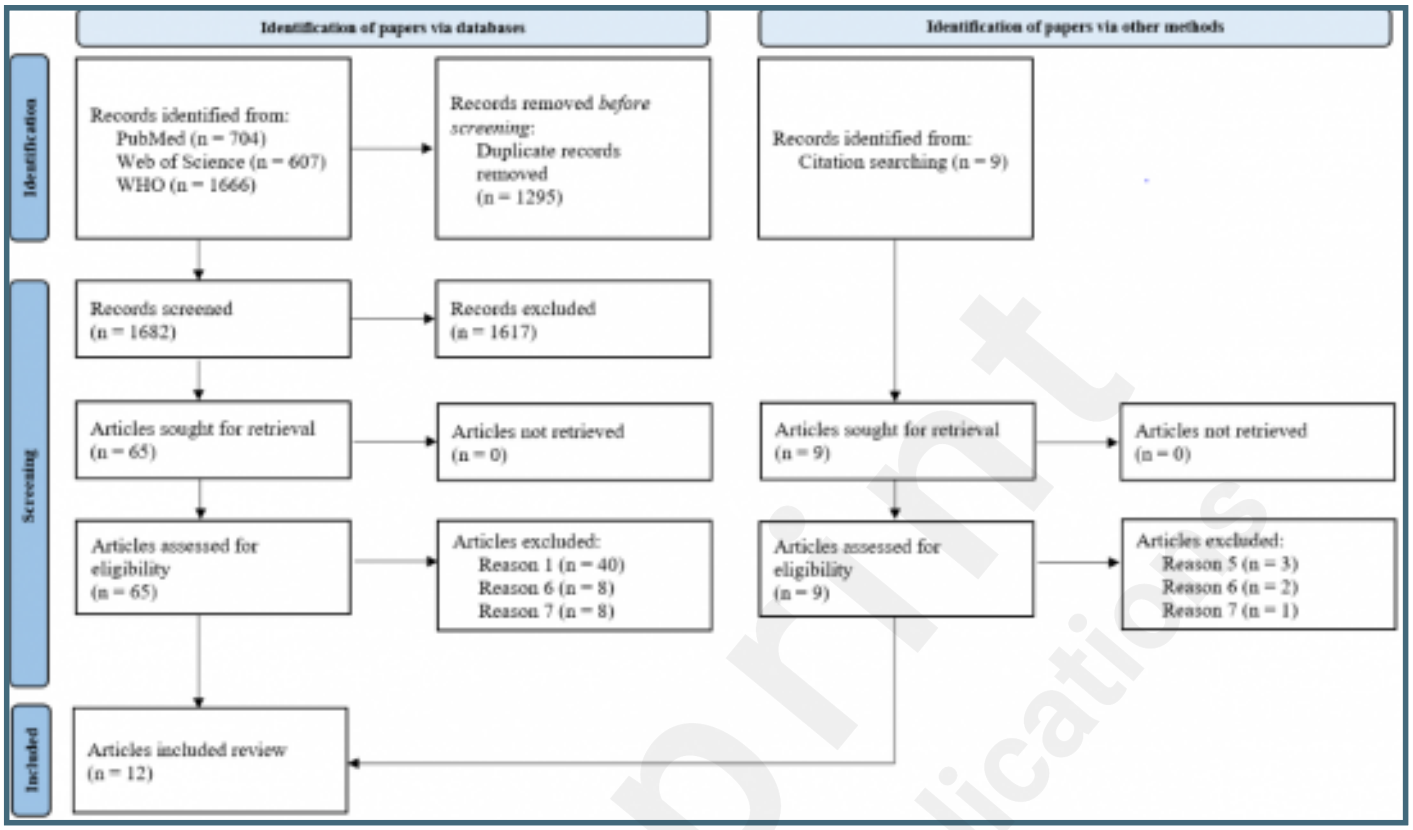
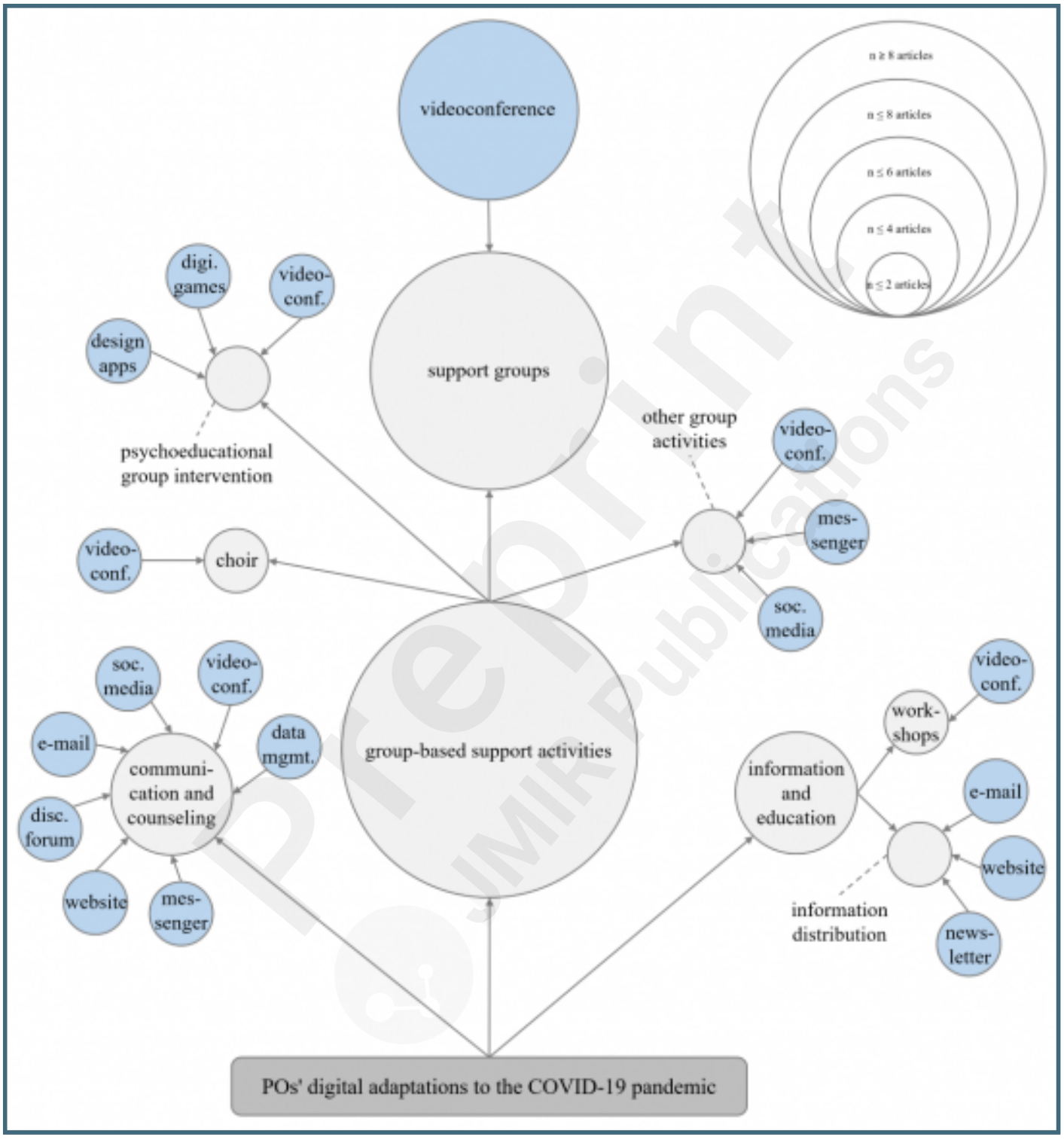
Supplementary Files

Figures

PRISMA flow diagram of the selection process during the initial search.



PO activities and services digitally adapted during the COVID-19 pandemic (grey bubbles) and the technologies used (blue bubbles).



Multimedia Appendixes

PCC Mnemonic and Search Strategies.
URL: http://asset.jmir.pub/assets/3c4a2b3bda7342447d0e58b2bf8c5a2d.pdf

PRISMA Flowchart for the Update Search.
URL: http://asset.jmir.pub/assets/d7d7bae950ec39a3eee36294b5a5722f.pdf

Characteristics of Included Articles and POs.
URL: http://asset.jmir.pub/assets/d73b293433a966ea0ae58326f6a4a4fd.pdf

Consolidated Findings on POs' Digital Adaptations of Group-Based Support Activities.
URL: http://asset.jmir.pub/assets/f9730299c5b5f26f01a43c8e854453eb.pdf

Consolidated Findings on POs' Digital Adaptations of Communication, Counseling, Information Provision, Educational Activities, and Other Operational Aspects.
URL: http://asset.jmir.pub/assets/e008908dd5d7fe40a94fefaff2780370.pdf