

# The lived experience of HIV-positive patients during COVID-19: a qualitative meta-synthesis

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## Abstract

**Introduction:** Patients infected with human immunodeficiency virus (HIV) face additional challenges due to the COVID-19 pandemic spreading. It is crucial to perform a qualitative synthesis to gather, evaluate, and combine the existing qualitative findings as evidence for developing interventions. Therefore, this review aimed to present the experience of HIV-infected patients during the COVID-19 pandemic.

**Material and methods:** Meta-aggregation approach enabled the analysis of studies published in English between January 2020 and July 2023, while methodological quality of studies was evaluated using Joanna Briggs Institute (JBI) qualitative assessment and review instrument. Dependability and credibility of synthesized findings were assessed with ConQual guide. Five thematic content analyses and three phenomenological studies with an overall quality score of 70-100% were included.

**Results:** The effective synthesis and aggregation of research findings from 213 participants in the eligible studies resulted in three distinct categories. Psychological distress, HIV care management, and social support were the three composite categories obtained from the results of qualitative studies. The ConQual score showed that two synthesized findings had a moderate rating.

**Conclusions:** Overall, patients with HIV were challenged due to the advent of COVID-19, including psychological distress and the need for customized disease management. These issues call for heightened support from society and healthcare professionals.

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**Key words:** COVID-19, experience, meta synthesis, qualitative research, HIV.

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## Introduction

The COVID-19 pandemic has been considered one of society's main problems in recent years [1]. COVID-19 has caused 1.5 million deaths worldwide, and many have to deal with its consequences [2]. This disease produced health problems, created economic crisis in many countries, and among people in the affected communities [3]. The World Health Organization (WHO) recommendations have prompted several prevention strategies, including lockdowns, social distancing, testing and contact tracing, and a shift towards remote delivery of health services through tele-medicine, such as text messages and phone calls [4]. In this sense, during this period, patients have faced numerous issues, including access to health centers and treatments [5]. Both the COVID-19 pandemic and related preventive measures have been likely to impact the health and well-being of people living with human immunodeficiency virus (HIV) [6]. For these individuals, who have been living with HIV for many years, the COVID-19 pandemic has brought back memories of the acquired immunodeficiency syndrome (AIDS) pandemic, including legislation that contributes to blame, harm, and stigma as well as efforts to combat HIV/AIDS [7]. Between May 8, 2020 and July 8, 2020, a survey was conducted among 653 individuals. The results showed that 77.6% of respondents ( $n = 501$ ) reported feeling more anxious, 71.8% ( $n = 464$ ) stated being more depressed than usual, while 19.8% ( $n = 128$ ) had suicidal thoughts since the start of pandemic. Respondents also expressed concerns about running out of HIV medication (40.7%,  $n = 264$ ), accessing HIV services (38%,  $n = 246$ ), and other health facilities (63%,  $n = 408$ ) [7]. In the past three years, several qualitative studies have been published to investigate HIV patients during COVID-19. There are multiple studies on HIV patients' experiences from psycho-social perspectives [8, 9]. Some studies highlighted the experiences of service accessibility, with patients' experience and healthcare delivery assessed. In qualitative research, beliefs' understanding, perspectives, needs, and values were assessed, revealing more details than quantitative studies. Qualitative research focus on specific phenomena that occur in unique situations and special experiences of individuals [10]. Stress and anxiety about virus contamination, death, unemployment, and loss of income, were expressed. Also, social stigmatization and dealing with HIV were among the findings of qualitative research [11, 12]. Qualitative synthesis is a review method for integrating or comparing findings from qualitative studies [13]. The knowledge accomplished from the results of this review process can create a fresh hypothesis, a wider inference of the findings, or an explanatory rendering [14]. Thus, synthesizing studies across countries and cultural contexts can offer a greater understanding of the psychological experiences of HIV-positive patients during the COVID-19 pandemic.

The purpose of this study was to integrate the experiences of HIV-infected patients during the COVID-19 pandemic through the synthesis of qualitative evidence.

## Material and methods

The process of meta-synthesis involves a purposeful approach to gather and evaluate multiple qualitative studies, which focus on a specific theme or topic [14]. The goal of this process is to create comprehensive and meaningful interpretations of the findings. In our study, we used a combined methodological model according to Noblit and Hare as well as that of Sandelowski and Barroso [15]. This model consisting of seven stages, is a widely used framework that enables the synthesis of diverse studies and extraction of a holistic interpretation (Figure 1).

### Step 1: Selecting the specific phenomenon to be examined

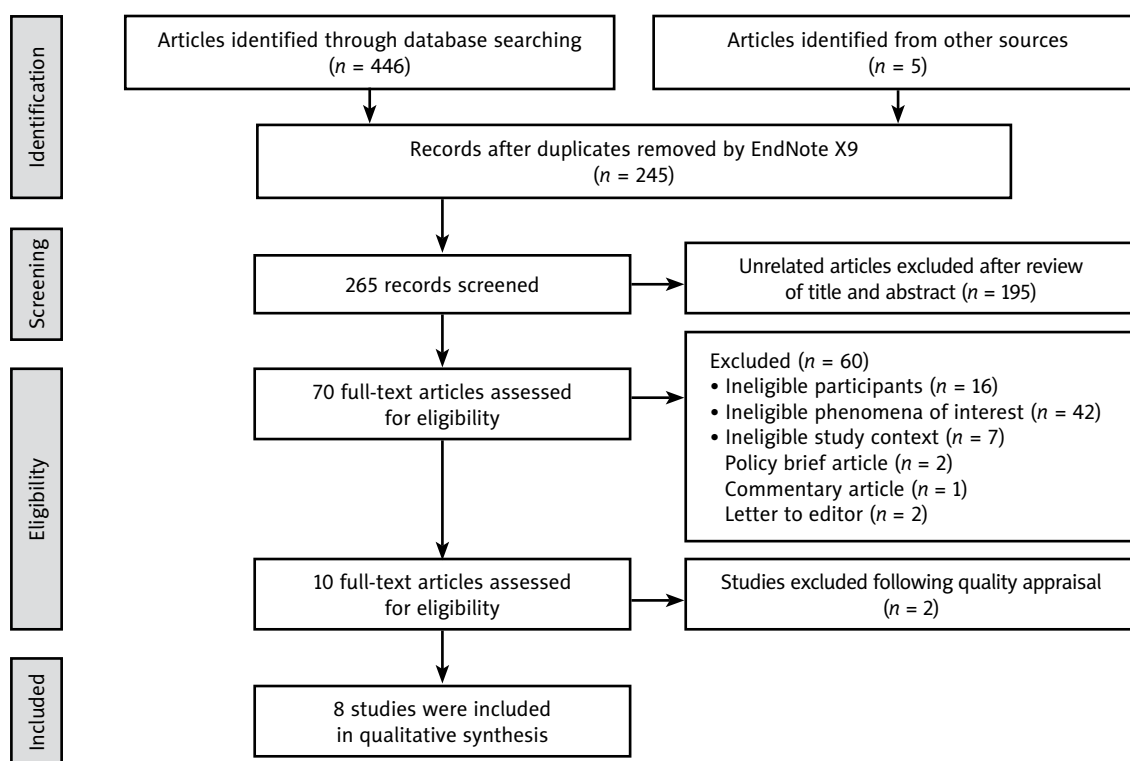
The objective of the study was to recognize contemporary problems and bridge the gaps in practice by constructing conceptual frameworks of the relevant phenomenon. The research adhered to Finfgeld's meta-synthesis guidelines [16], and a thorough review of the literature was performed to meet the study goals. To accomplish this, the study formulated the following research inquiries:

1. What philosophical and theoretical perspectives are currently reflected in the experience of HIV and the COVID-19 pandemic?
2. What research methods were used in the selected studies?
3. What are the primary themes that arise from the chosen studies?

### Step 2: Deciding and choosing subjects related to the purpose of the study

The meta-synthesis methodology used in this study followed the steps outlined by Sandelowski and Barroso [15], described in the section below. Abstracts and full-text papers published in databases, such as PubMed, Scopus, Web of Sciences, and Google Scholar Index, were considered. Key terms used were ("COVID-19" OR "Coronavirus Disease") AND ("Experience," "Attributions," "Lived Experience," "Patient Care Experience," "Beliefs," "Real-Life Experience," "Perceptions," "Perspectives," "Understanding," and "Values") AND ("Qualitative," "Interpretive," "Phenomenology," "Hermeneutics," and "Phenomena"). To broaden the scope of search, a range of strategies were employed, including using MeSH headings, free-text searches, Boolean operators, and truncation techniques. Inclusion criterion was population of HIV patients. This qualitative study mainly focused on studies on illness experience, healthcare service accessibility during COVID-19, problems created by the pandemic, and patients' own experiences. Articles published between January 2020 and July 2023 were considered.

Exclusion criteria were quantitative, case study, and other opinions, population of healthcare workers and sexual workers, who have not been identified as having HIV/AIDS, studies on job dimensions and experiences with tele-health.



**Figure 1.** Diagram of the selection process of studies related

Experiences about tele-health only focused on this topic, and did not consider other experiences, which patients have had during COVID-19.

### Step 3: Full reading and re-reading of related articles

The main objective of this section was to assess the quality of studies included and findings. The process involved extensive reading and re-reading of each study, providing a comprehensive understanding of their themes. Analysis of each study was conducted to identify and tabulate country, discipline, domain, and methodology for further analysis purposes. Using the standards for reporting qualitative research (SRQR) [17], an evaluation was done to determine the quality of each study.

### Step 4: Identifying how different themes are inter-connected

This step, known as the association search, is a critical component in any data analysis process. The utilization of the WFWCF (warming I-freezing-warming II-comparing-filtering) analysis [18] process enabled to extract findings, which were both rigorous and dependable. The process of thematic synthesis [19] was carried out in both stages I and II, focusing on the topic of warming. Our process involved coding each line of data, and subsequently converting the codes into

detailed sub-descriptive and descriptive themes. The themes classified as even were confirmed, while those categorized as odd were removed based on their relevance in both stages of warming I and II. There was a freezing time of two weeks between the analysis of data. The purpose of this phase was to conclude concepts with variation. Categorizing the descriptive themes led to the identification of analytical themes.

### Step 5: Minimizing studies to one study

This process was challenging. In this step, we used approaches-conceptual translation that employed refutational translation, and the quality of studies and final concepts depicted in one study were assessed. In step 6, new interpretation of analyzing studies and concepts were provided. Whereas, drafting of the report for the publication process were included in the final, 7<sup>th</sup> step.

### Dependability and credibility assessment

To establish confident synthesized findings, dependability and credibility of methodological research should be considered. In this study, ConQual score was employed to evaluate the quality of articles [20]. The ConQual score uses a level rating system, such as high, moderate, low, and very low. Results acquired through meta-synthesis directly correlate with out-

comes from each study. The analysis of methodological quality appraisal scores (questions 2, 3, 4, 6, and 7 in JBI-QARI [Joanna Briggs Institute qualitative assessment and review instrument]) helped establish the level of dependability by evaluating a study's compliance with specified guidelines [21]. Dependability is categorized based on the number of answers to each question. If questions 4 to 5 are answered "Yes", dependability is considered high. In case of two or three "Yes" answers, the rating is lowered to a moderate level. Downgrading takes place when there is a solitary "Yes" response, shifting the rating from high to low or moderate to very low.

## Results

The primary search yielded a total of 446 studies, demonstrating the extensive research conducted on the particular topic. With such a significant number of studies, considerable attention was dedicated to this subject matter by scholars and researchers. However, upon closer examination, 245 duplicated articles were identified. In the titles and abstracts investigation, 195 out of the remaining 203 studies were excluded, followed by exclusion of another 70 studies based on the inclusion criteria during initial screening. Finally, a comprehensive assessment of the methodology was conducted on 10 selected full-text articles, to ensure that only high quality studies were included in the analysis. Though, after critical appraisal, the final analysis included only 8 eligible studies.

### Characteristics of the included studies

Table 1 displays the features of the studies included.

### Reliability and trustworthiness of the method used and the validity of synthesized results

The studies had a range of overall quality, from 70% to 100%, with lower-scoring research giving "No" response for questions 6 and 7. The dependability ranking received a moderate rating. Also, a moderate rating was given to the credibility of each synthesized finding due to the presence of both unequivocal and equivocal findings. Two synthesized findings were generated and rated as moderate in the ConQual score.

### Synthesized findings

Figure 2 illustrates the presented findings, categories, and synthesized conclusions. The combination of 12 findings resulted in the integration of synthesized finding 1 into a single category.

#### Category 1: Psychological distress

Patients with HIV during the COVID-19 pandemic shared their experiences of fear and anxiety. These individuals,

who already faced a daily battle against a chronic illness, were confronted with an additional threat posed by COVID-19. Their fears were rooted in concerns over potential complications due to compromised immune systems, as they were at a higher risk for severe illness if infected. For example:

*"It [HIV] made my fear [of COVID-19] more significant because my status is not under control."*

Other participant said:

*"I feel very kind of worried, not kind, very worried about getting it [COVID-19] by touching the wrong thing or you know, just making a mistake. And then, I could probably die. And I feel like I'm more at risk than other people, like even if I'm undetectable, I just feel like I would die."*

Furthermore, many HIV-positive patients experienced disrupted access to healthcare services and medications during this unprecedented time, exacerbating their anxieties. The constant stream of information about the coronavirus could be overwhelming and confusing for these vulnerable individuals, leading them to feel even more anxious about their well-being. Some patients expressed the fear of loneliness, while loss of job and decrease in income caused them anxiety in controlling the disease and taking medicine as well as consuming the necessary food. For example:

*"I lost my job...And it felt like I was going crazy to get my phone got cut off. You know? So, a lot of little things I've been through, to struggle with."*

The fear of being labeled by others (stigma) was one of the issues that HIV patients considered, found in several articles related to this issue. The fear of being alone during lockdown and lack of support from medical staff and friends were also mentioned.

#### Category 2: HIV care management

Navigating the healthcare system can be challenging for individuals living with HIV, but the COVID-19 pandemic has introduced even more obstacles. Disruptions in healthcare services have led to concerns about accessing necessary HIV treatments and clinic visits. Many patients faced cancellations or delays of their appointments, causing anxiety and uncertainty about their health status. The fear of contracting COVID-19 while visiting healthcare facilities has also deterred some from seeking the care they need, leading to potential gaps in the treatment. For example:

*"...I'm really afraid to go in and out of hospitals now. So, I canceled my appointment."*

Some patients could not connect with social media and tele-health, which did not allow them to use this methods. Therefore, not using this relationship with medical staff caused poor communication and failure to properly manage the disease. For example:

*"Sometimes I have a network failure and I am not able to meet with him [doctor] and I miss my appointment."*

Tele-health has emerged as a preferred option among individuals, who encountered obstacles in attending traditional in-person appointments. One of the key advantages of tele-health is its ability to address geographical barriers,

Table 1. Features of studies included for analysis

Study	n	Participants	Setting and type of gathering data	Data analysis style reported
Bleasdale <i>et al.</i> , 2021 (USA) [32]	26	The majority self-identified as males (52%), Black/African American (68%), and straight/heterosexual (60%). Ages ranged from 24 to 85 years (M = 40.4 years, SD = 17.9)	A semi-structured interview guide was used. Interviews ranged in length from 23 to 53 min. Interviews were conducted via phone, Zoom, or FaceTime	Thematic content analysis reported semantic-level themes
Baim-Lance <i>et al.</i> , 2022 (USA) [11]	80	The sample consisted of 41 self-identified males, 38 females, and 1 transgender female. The median age was 59 years (IQR: 55-64)	Open-end question that the interviewee encourage respondents to explain more. The interview finished by asking participants to share anything else important about their physical or mental health at present	Qualitative analyses utilized thematic coding to reveal common experiences
Devlin <i>et al.</i> , 2022 (USA) [33]	25	Women living with HIV, 18 (72%) identified as Black/African American, median age was 39 (range 23-62) years, and 5 (20%) had been diagnosed with COVID-19 before the interview	A semi-structured interview guide was used. All interviews were conducted via telephone or Zoom by trained research staff in a private and secure location	Thematic content analysis reported
Garcia <i>et al.</i> , 2022 (Ecuador) [8]	10	Not reported	Study data were collected through in-depth interviews according to Ander-Egg	Qualitative data were analyzed using Atlas.ti v. 9. In brief, a hermeneutical unit was generated using codes, citations, and analysis networks to facilitate the interpretation of information contained in each interview
Sharma <i>et al.</i> , 2022 (Uganda) [34]	31	Participants included men, women, men having sex with men (MSM), sex workers, and perinatally infected young people, aged 18 to 24 years, who receive services during treatment	Focus group discussion was used to attain information. Interpretive phenomenological was applied for study design	Thematic analyses were used to understand HIV stigma experiences and manifestations
Mukamba <i>et al.</i> , 2022 (Zambia) [9]	25	The median age of the participants was 43 years, with an interquartile range (IQR) of 21-58, 52% were females (n = 13), and 64% were from health centers. Almost three-quarters (72%) of the participants were married, and about one-third (36%) were unemployed	A semi-structured interview guide was used. The median duration of interviews was 56 min. Interview notes together with all audio-recorded interviews (n = 24) were used to develop analytic memos	Matrix analysis was applied to finalized memos. The main deductive themes (matrix domains) were drawn from the interview guides, and a summary Excel-based template was developed
Derbew <i>et al.</i> , 2022 (Ethiopia) [25]	16	The average age was 40 years, and over half of the sample (62%) were females. The mean age of HIV infection was 7.68 years	In this phenomenology study, an in-depth interview guide and digital recorder were used to explore the lived experience of HIV people on ART in the context of COVID-19	Atlas.ti qualitative data analysis software version 7 was employed to facilitate data analysis. Analysis followed reading of transcripts, developing and applying coding, displaying data, data reduction, and interpretation
Klau Fau <i>et al.</i> , 2023 (Indonesia)	21	The participants were males (n = 14) and females (n = 7) living with HIV. Their age ranged from 25 to 53 years, with majority in the group aged 31 to 40 years (n = 12), followed by 41 to 50 years old group (n = 6)	Data collection was conducted using one-on-one and face-to-face in-depth interviews from April 2022 to May 2022. Interviews lasted for 35-50 minutes, and were conducted in Indonesian language	Data analysis was performed manually and guided by five steps of qualitative data analysis included in Ritchie and Spencer's qualitative thematic framework analysis



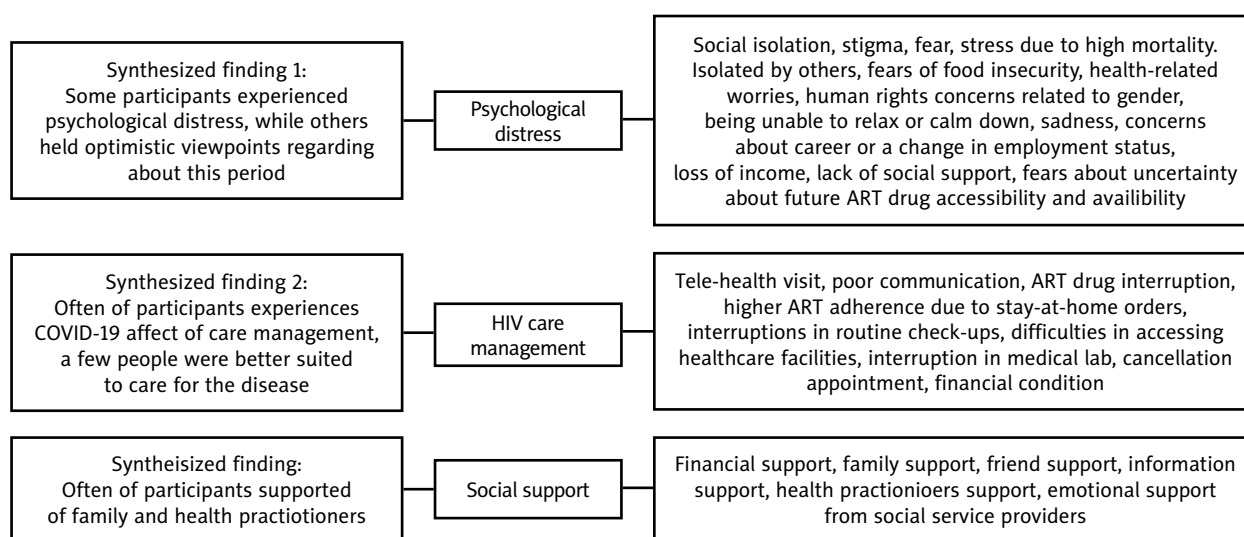


Figure 2. Summary of findings and categories for each synthesized finding

making it more accessible for patients residing in remote areas with limited healthcare facilities. Additionally, individuals facing physical limitations or disabilities find it significantly easier to engage with healthcare professionals through tele-health platforms, eliminating the need for transportation and potential mobility challenges. Moreover, tele-health can be particularly beneficial for patients with mental health conditions, such as social anxiety or agoraphobia, who may experience significant distress when attending face-to-face appointments or crowded waiting rooms:

*“Virtual appointments saved me from the burden of transportation costs because there was a time when I didn’t have proper employment and I didn’t have any money to take the bus [to the clinic].”*

### Category 3: Social support

The COVID-19 pandemic has forced HIV-positive individuals into prolonged periods of social isolation and loneliness. The fear of contracting the virus, coupled with the need to adhere to strict preventive measures, has limited social interactions and support networks. This isolation had a detrimental effect on mental well-being, highlighting the need for innovative support systems to mitigate its impact. The pandemic has dramatically altered the dynamics of relationships and support networks for individuals living with HIV. Many experienced a shift in the way they interact with friends, family, and support groups due to social distancing measures and travel restrictions. This change resulted in a loss of in-person support and a reliance on virtual platforms, which may not adequately meet the emotional needs of HIV patients.

### Emotional support and peer networks

Emotional support played a crucial role in helping HIV-infected patients coping with the added stressors of

the pandemic. Peer networks and support groups become invaluable resources for individuals to share experiences, exchange information, and find solace, knowing they are not alone. These connections provided a sense of belonging and understanding, empowering patients to navigate their emotional ups and downs of living with HIV during COVID-19.

## Discussion

With the emergence of the COVID-19 pandemic, society faced many challenges, high infection intensity, and unprecedented mortality, which the WHO and other countries have been having difficulty controlling. Meanwhile, many patients have been facing challenges. Elderly people, immunocompromised patients, patients with cardiovascular diseases, cancer patients, and those who used immunosuppressive drugs, were in a worse position in acquiring the disease. One of the high-risk groups were patients with HIV, who gained new experiences in the era of COVID-19. However, HIV-positive patients also faced many challenges before COVID-19, including lack of support from people around them and society, stigma and labeling, worries about getting sick and losing friends and support from society as well as treatment processes. In the meta-synthetic analysis, qualitative studies on the experience of HIV patients were examined, which ultimately provided insights into their experiences during the COVID pandemic. In the combination of the results, one of the obtained classes is psychological distress. The results of qualitative studies of patients’ experiences showed that they faced many experiences during this period, such as worries of contracting the disease and losing their life, worries about the lack of supply of medicines, fears of job loss and job disorders, worries about accessing healthy food, lack of attention from the treatment staff, no support from society, and loneliness. Experiences, such as the fear of contracting the disease, loss of life, lack of access to medi-

cine, and control of the disease, were also expressed by other patients. Patients with COVID-19 [22], those with multiple sclerosis [23], and kidney transplants [24], had comparable experiences. Similar to HIV patients, they had to cancel doctor's appointments due to the fear of contracting the coronavirus. What distinguishes the experiences of these patients from other chronic disease patients, is the feeling of greater danger and the notion of lack of support from healthcare centers due to the shame of this disease. Therefore, these patients needed more support from the treatment staff and healthcare workers, with multidisciplinary professional teams to support them is necessary. In addition, there was the concern of job loss and lack of supply of drugs used, which were distinct experiences of these patients compared with other high-risk groups. What was not present in the experience of these patients compared with other patients, was the concern about physical fitness that kidney transplant patients and dialysis patients had expressed [24].

Another main category was the combination of outcomes related to patients' self-management. Several patients had canceled their doctor appointments. Also, they did not use their medicines due to the long duration of visits and referrals to medical centers [25]. Several patients were not familiar with tele-health [11] and did not feel safe with it. Numerous patients described the telephone and internet contacts with their doctor as good, and stated that with this method of communication they were able to share their private information with the doctor and even expressed their mental state better in the COVID-19 era. In the analysis, most of the patients expressed their treatment status as bad [11]. Self-management of the disease, using prescribed drugs, and regular check-ups depend on the mental state of a person, individual self-efficacy, and the necessary support from society and healthcare personnel [26]. Therefore, in this era, HIV patients require special attention to meet their needs. Social support was also among the classes obtained from the combination of results. HIV/ AIDS patients, same as other patients, needed support from their family, friends, and healthcare staff. Social support refers to the informational support, material support, and emotional support. The need for social support was also observed in the experience of other chronic cases and even patients with COVID-19 [27, 28]. Cancer patients in the era of COVID-19 considered one of the important factors in planning to deal with both the coronavirus and their disease as well as the support of people around them and healthcare staff. They felt satisfied that their needs were responded by society [29]. Heart failure patients also stated that support from people around them was one of the important factors in dealing with the challenges while facing this special situation [29-31]. Therefore, due to social distancing in the COVID-19 pandemic, the fear of lack of support from society as well as the special condition of this disease, patients with HIV required more attention in these eras, while many patients underlined the experience of not having enough support from society.

Table 2. Critical appraisal of the included studies

Study	JBI-QARI										ConQual score		
	Q1	Q2	Q3	Q4	Q5	Q6	Q7	Q8	Q9	Q10	Total (%)	Dependability	Credibility
Baim-Lance <i>et al.</i> [11]	Yes	Yes	Yes	Yes	Yes	No	No	Yes	Yes	Yes	80	Moderate	Synthesized finding 1: Moderate (11 unequivocal findings, 5 equivocal findings) Synthesized finding 2: Moderate (8 unequivocal findings, 2 equivocal findings)
Bleasdale <i>et al.</i> [32]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	90	High	
Derbew <i>et al.</i> [25]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	90	High	
Devlin <i>et al.</i> [33]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	90	High	
Fauk <i>et al.</i> [35]	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	Yes	100	High	
Garcia <i>et al.</i> [8]	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	70	Moderate	
Linnemayr <i>et al.</i> [36]	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	70	Moderate	
Mukamba <i>et al.</i> [9]	Yes	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	90	High	
Parisi <i>et al.</i> [12]	Yes	Yes	No	Yes	Yes	No	No	Yes	Yes	Yes	70	Moderate	
Sharma <i>et al.</i> [34]	Yes	Yes	Yes	Yes	Yes	No	Yes	Yes	Yes	Yes	90	High	

Q1: "Does there exist similarity between the articulated philosophical viewpoint and the employed research methodology?" Q2: "Does the research methodology align with the study question or objectives?" Q3: "Does congruence exist between the research methodology and data collection methods employed?" Q4: "Does the research methodology align with the representation and analysis of data?" Q5: "Does the research methodology correspond with the interpretation of the results?" Q6: "Is there a statement that identifies the cultural or theoretical background of the researcher?" Q7: "Is there any consideration given to the reciprocal influence between the researcher and the study?" Q8: "Is there sufficient representation of participants and their perspectives?" Q9: "Does the research adhere to contemporary ethical standards or, in the case of recent studies, is there evidence of ethical clearance from a suitable regulatory body?" Q10: "Do the conclusions presented in the study report stem from a thorough analysis or interpretation of the data?"

JBI-QARI – Joanna Briggs Institute qualitative assessment and review instrument

## Limitations and strengths

The design of the studies in this review was mainly based on thematic content analysis and phenomenology using semi-structured discussions. Therefore, this review lacked the diversity of research designs, which affected the comprehensiveness of the synthesized findings. The quality of qualitative studies used in this analysis needs an improvement. Most of the studies did not mention the cultural background and characteristics of the researcher and interviewer. In qualitative studies, the quality of research findings may be influenced by the researcher. A person's ideas, opinions, and statements can affect the results and status of a study. In addition, the studies, which met the inclusion criteria were from 6 countries. Every country has its own culture, and there is cultural diversity in different countries. Therefore, to better understand the feelings and experiences of patients, it is necessary to consider cultures of different countries. The strength of this study was the summarizing of the study results, which would be helpful for scientists and researchers.

## Conclusions

In the current study, meta-synthetic approach was used to combine the findings of the qualitative studies from 6 countries (i.e., United States, Indonesia, Ecuador, Uganda, Zambia, and Ethiopia). Whereas dependability and credibility of the synthesized findings were evaluated with the average quality rating system. The findings of this review provided in-depth interpretations of the experiences of HIV/AIDS patients during the COVID-19 epidemic. Therefore, according to the obtained results, healthcare professionals and community should pay more attention to the special needs of patients and their mental states, trying to resolve them. Furthermore, while supporting patients, they should be encouraged to adopt effective coping strategies to promote mental health. It is suggested to use this study in a designing model for better understanding of patients' needs during crises.

## Disclosures

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2. Assistance with the article: None.
3. Financial support and sponsorship: None.
4. Conflicts of interest: None.

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