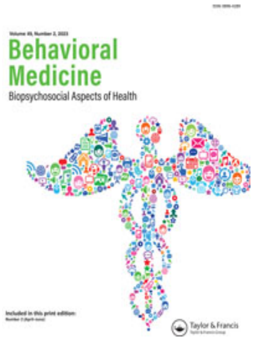

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Behavioral Medicine

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/vbmd20

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To cite this article: Andrea Rodríguez-Prat, Denise Pergolizzi, Iris Crespo & Cristina Monforte-Royo (2023): Experiences of Isolation among Patients Hospitalized during an Infectious Disease Outbreak: A Systematic Review and Meta-Ethnography, Behavioral Medicine, DOI: 10.1080/08964289.2023.2214717

To link to this article: https://doi.org/10.1080/08964289.2023.2214717

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BEHAVIORAL MEDICINE
https://doi.org/10.1080/08964289.2023.2214717

Experiences of Isolation among Patients Hospitalized during an Infectious Disease Outbreak: A Systematic Review and Meta-Ethnography

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ABSTRACT

Hospital isolation is common for people during infectious disease outbreaks. Anxiety, stress, depression and other psychosocial outcomes have been reported due to these measures. However, there is scarce evidence about the experience of being isolated and about best practices for empathic clinical care in these circumstances. The aim of this study was to explore the experience of isolation on patients hospitalized during an infectious disease outbreak. A systematic review and meta-ethnography was carried out. A search strategy was applied to the PubMed, CINAHL, Web of Science, and PsycINFO databases on April 14, 2021 and again May 2, 2022. Data synthesis was conducted using Noblit and Hare's method of qualitative thematic synthesis. Twenty reports were included in this review: 16 qualitative, two mixed-methods (only the qualitative part was analyzed), plus 2 personal view pieces. They described the experiences of a total of 337 people hospitalized and isolated with an infectious disease. Following analysis and coding of data, four themes emerged: 1) Feelings triggered by isolation; 2) Coping strategies; 3) Connection/disconnection; 4) Factors that influence the experience of isolation. Despite a sensitive search strategy, limited studies represent patient experiences using qualitative methods. The experience of isolation among patients hospitalized during an outbreak is characterized by fear, perceived stigma, and a sense of disconnection from others and the outside world due to a lack of information. Fostering a person-centered care model could help hospitalized patients develop adaptive mechanisms that minimize the impact of isolation.

ARTICLE HISTORY
Received 27 September 2022
Revised 28 April 2023
Accepted 11 May 2023

KEYWORDS
infectious disease; outbreak; patient behavior; patient isolation; systematic review

Introduction

Since the global COVID-19 outbreak, an estimated 764 million people have become infected and over 7 million have died.[1] To restrict further spread of infection, many governments implemented quarantine measures, including hospital isolation. Consequently, those people who required medical attention not only faced a life-threatening illness but also did so alone. Isolated patients may thus have experienced greater loneliness, uncertainty, and lower quality care, all of which have been linked both directly and indirectly to negative consequences for health, wellbeing, and even mortality in the general population.[2,3] Exploring the meanings that patients ascribe to the experience of isolation may therefore shed light on the wider impact of illness during an outbreak.

Hospital isolation has been a commonly used measure in the context of outbreaks. Studies conducted during outbreaks of SARS (Severe Acute Respiratory Syndrome) in China[4] and Ebola in Liberia[5] and Uganda[6] focused on mental health problems and emotional distress due to hospital isolation. In a similar vein, an abundance of recent opinion and review articles have emphasized the negative psychological impact of COVID-19.[7–10] The high mortality rates in the COVID-19 pandemic and previous epidemics suggest that additional emphasis can be placed on other impacts of an existential (death and dying) and social (absence of family) nature. For example, patients' may fear dying alone, which is contrary to the notion of a 'good death'[11] and the premises of the person-centered model of care,[12] where the ideal is for people to make their own decisions regarding their preferences, needs,

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Supplemental data for this article can be accessed online at https://doi.org/10.1080/08964289.2023.2214717.

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and values, which can imply to choose where they die and to be surrounded by loved ones; and, crucially, it ensures that people are always treated with dignity, compassion and respect. The psychological and existential distress due to a personal crisis, especially when facing death and dying, has been well documented in other illnesses[13] but is not well recognized in the context of infectious diseases. This may be especially important as death anxiety is posited to play a role in various psychological conditions.[14]

To date, the impact of outbreaks on psychological wellbeing,[15] or on existential (hope and meaning in life) and social dimensions (perceived social support[16]) has primarily been explored through surveys in the general population. Quantitative research has shown that patients in hospital isolation can experience a large number of negative effects related to the nature of the illness, its treatments, the environment, and care received[17,18] that are dependent on the patient's subjective perspectives and responses. Current understanding of the complex and interacting circumstances that influence the negative impacts of hospital isolation is limited, yet is vital for improving the professional and public health response in the context of current and future pandemics. Qualitative research has been conducted,[4,5] however, has little influence to inform practice or policy changes as individual studies. This systematic review with qualitative synthesis of research findings is, therefore, called to deepen our understanding of the impact that isolation may have on patients who are hospitalized, which is crucial to ensuring that all their needs are addressed. The aim of this review is to explore the experience of isolation on patients hospitalized during an infectious disease outbreak from the qualitative point of view and to bring more comprehensive details about this phenomenon.

Methods

Design

We conducted a systematic review and meta-ethnography (a kind of qualitative systematic review) as described by Noblit and Hare.[19] This is an inductive method that involves making constant comparisons between the results obtained in primary studies (original published articles) in order to achieve a final interpretative synthesis, rather than simply aggregating the data reported by the original authors of each study. In this case we included qualitative studies and mixed-methods studies, but in this case, we only analyzed the results from the qualitative methods.

Search methods and inclusion criteria

The review was conducted in accordance with PRISMA guidelines.[20] The search strategy combined MeSH terms with free-text searching and was applied to the PubMed, CINAHL, Web of Science, and PsycINFO databases.

The inclusion criteria were: 1) that participants in the primary studies were patients who had been hospitalized or isolated in medical units during infectious disease outbreaks; 2) that the study explored patients' experiences of isolation; 3) that articles were published in English; and 4) Research articles published since 2000. The sole exclusion criterion was that participants were not adults (≤18 years). The study selection process was performed by two researchers using Rayyan,[21] a screening tool that facilitates the process of the selection of the studies per peers, and a manual search of reference lists. Screening involved selection of retrieved citations by title, abstract, and full text. Reasons for exclusion of full-text articles were recorded. Any discrepancies between the two reviewers were resolved by discussion within the research group. Figure 1 shows the flowchart for study selection performed on May, 2022.

Quality appraisal

Qualitative studies were evaluated using the Standards for Reporting Qualitative Research (SRQR) guidelines,[22] one of the most used checklists among qualitative researchers to assess quality of the qualitative studies, with the exception of two reports whose design was not compatible with these guidelines. The Mixed Methods Appraisal Tool (MMAT)[23] guideline was used to assess the quality of the mixed-methods studies included in the review. We considered that all the studies could contribute to an understanding of the phenomenon, and consequently none of the reports was excluded due to its quality. However, the quality appraisal analysis reports a picture that helps the reader to understand the type of studies included in the review.

Analysis

Three researchers (AR, DP, CM) analyzed the studies in line with Noblit and Hare's meta-ethnographic method.[19] The supplementary file includes a detailed information about how this analysis was carried out. Here we only summarize the main parts of the synthesis process. The analysis began by reading the included studies (especially considering the quotations) in order to identify key concepts in each of them, and to determine how these concepts were present across the studies. We created a chart showing the categories that emerged from the studies (more descriptive level), and this served as the basis for obtaining themes and sub-themes from each study (more interpretative levels that encapsulate the categories found in the different studies [see Table 1]). We analyzed all the studies considering the emerged categories. This process implied several readings of the studies included in the review.

The analysis was carried out using the software ATLAS.ti 9.0.

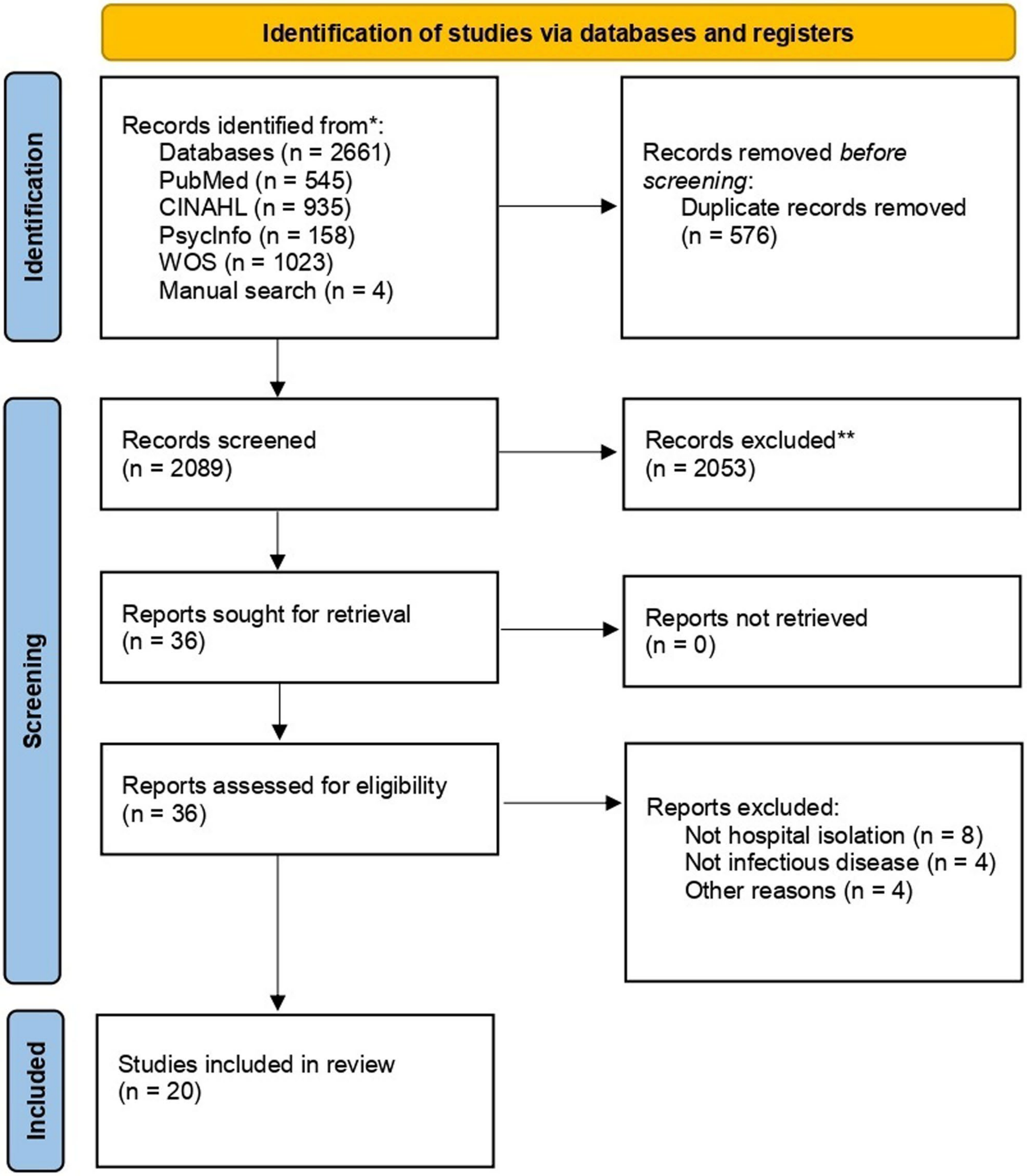

Figure 1. PRISMA flowchart of the selection of the studies.[20]

Results

Study characteristics

Twenty reports were included in this review (16 qualitative, two mixed-methods [only the qualitative part was analyzed], plus 2 personal view pieces). They were published between 2005 and 2021 and reported the experiences of a total of 337 people in eleven different countries: Australia, China, France, Iran, Singapore, Sweden, Taiwan, The Netherlands, Turkey, USA (see the characteristics of the included studies in Table 2). As per the diagnoses, we included studies with samples of COVID-19, hemorrhagic fever, MRSA (Methicillin-Resistant Staphylococcus Aureus), SARS and tuberculosis.

Thematic synthesis findings

Four themes emerged from the analysis: 1) Feelings triggered by isolation; 2) Coping strategies; 3) Connection/disconnection; and 4) Factors that influence the experience of isolation.

Feelings triggered by isolation

This theme refers to all those feelings, emotions, and thoughts that participants experienced as a result of being isolated in hospital, and it comprised two sub-themes: fears and feeling rejected.

Fears. Fear was one of the most common features of participants' experience. Some of them expressed a fear of infecting others, especially family members and loved ones, but also health care staff. Fear of a bad death, of dying alone, or simply of death itself was also mentioned by some patients. Fear was related to various types of suffering (due to uncertainty about diagnosis and treatment, or in the form of physical and psychological distress caused by their situation), and in this respect some patients experienced despair:

I had a very difficult time for 5–6 days. Each breath was difficult for me […]. I thought about death. I was afraid that I would not see my family for the last time. I was not psychologically prepared […]. The issue was not only of whether one would be intubated, but the issue of death.[24(p156)]

Or: "I was genuinely frightened that I would never see my friends again. I was scared that I would not have the chance to get married or have children."[25(p13)]

Fear was also related to uncertainty regarding prognosis. In the study by Du et al.[24] with a sample of nurses, verbatims are collected that refer to concern about the persistence of symptoms and the side effects of treatments. Being health professionals, their fear was related to a greater awareness of the patient's negative prognosis, despite the uncertainty of the moment. In two studies, the high level of distress experienced led some participants to express a wish to hasten death, which was seen as a way of putting an end to their suffering.[25,26]

Feeling rejected. This sub-theme reflected the various ways in which participants, due to their contagious status, felt rejected by family members, neighbors, or work colleagues. The perception that health care professionals were afraid of becoming infected also led some patients to feel rejected:

I complained about the absence of nurses and the fact that they came to my bed only in emergencies. I thought the reason was that the medical staff feared me and the contagiousness of the disease and that they were negligent.[27(p334)]

This sense of rejection generated feelings of loss of control, guilt, and frustration at being unable to fulfill their usual roles in life. Guilt feelings were more intense among patients who were the primary caregiver for family members, and also when there was an economic impact on the family due to the patient being unable to carry on working. In some studies, participants mentioned that they felt as prisoners[27] to describe the experience of being isolated. The perception of guilt was common for patients when they felt responsible for their situation as this quotation shows:

While I thought I could leave the hospital, I was not discharged and felt very disappointed. I did not sleep very well and cried because of the pressure. I pressured myself too much. If I stayed for another week, I felt that my spirit was pushed to the edge.[28(p891)]

Perceived stigma was a common experience that emerged from the studies.[27–34] Patients expressed recognition of the fear of infecting others, the general uncertainty surrounding the health threat from their illnesses, combined with their isolation and being "separated from the world" both physically and socially as sources of this perceived stigma. At the same time, these factors also enhanced feelings of loneliness. Moreover, patients reported negative attitudes from some professionals or even a lack of care as additional triggers for perceived stigma.[35]

Feeling abandoned and isolated in a setting characterized by anonymity, and perceiving this growing stigma that was being attributed to infected patients produced a sense of rejection.

Table 1. Main themes, subthemes, and categories.

Themes	Subthemes	Categories
Feelings triggered by isolation	Fears	Abandonment
	Feeling rejected	Anonymity
		Being a burden
		Boredom
		Frustration
		Fear of death
		Fear of dying alone
		Fear of HP
		Fear of reinfection
		Guilty
		Pessimism
		Rejection
		Hopelessness
		Mental pain
		Loss of control
		Sense of failure
		Sense of powerlessness
		Stigma
		Suicidal ideation
		Uncertainty
		Worries
		Wish to hasten death as a way of ending suffering
Coping strategies	Finding hope	Acceptance
	Struggling with reality	Avoiding external reminders
		Avoiding memories
		Denial
		Faith
		Finding ways to enrich life
		Hope for recovery
		Learnings
		Not psychologically prepared
		Positive thinking
		Sources of strength
		Positive viewpoints
		Taking care of themselves to recover
Connection/Disconnection	Importance of human relationship	Awareness of patients' needs
	Lack of humanized care	Difficult relationship with healthcare providers
	Being informed	Family - decrease loneliness
		Fear of being killed by the medical staff
		Staff behavior
		Healthcare providers frustration
		Impersonalized care
		Importance of information
		Importance of family
		Importance of human connection
		Lack of empathy
		Loss of communication
		Loss of intimate relationship
		Media - social representation - bad image
		Poor staff support
		Professional help to cope with the situation
		Staff support
		Power of human presence
		Use of technology
Factors that influence the experience of isolation	Personal impact	Blaming yourself
	Facility-related factors	Cold during hospitalization
		Deprivation
		Facing death
		Hospital - structures - burden
		Confidence in Hospitalization: way of spare other from getting infected
		Importance of religion and values
		Loss of normal life
		No food provided
		No proper protective measures
		Paying cost
		Personal loss
		Spiritual awakening
		Side effects of hospitalization
		Struggling with death
		system
		Types of hospitalization

Table 2. Characteristics of the included studies.

Author/s	Participants	Country	Design	Aims	Results
Mok et al.[24]	Ten nurses who had suffered from SARS	China (Hong Kong)	Qualitative study. Content analysis	To explore how nurses who had contracted SARS perceived the experience of illness and to uncover the principal concerns of the informants.	Nine categories were identified: uncertainty, information control, feelings of anger and guilt, lack of preparation and fear of death, feelings of isolation and loneliness, physical effects, support, change of perspective of life, and change of perspective of nursing.
Tirado[25]	One COVID-19 patient	USA	Personal experience	To auto-ethnographically describe his experience of being hospitalized due COVID-19.	Personal view.
Lin et al.[41]	Seventeen patients with fever who were quarantined in the fever screening station of a hospital emergency department	Taiwan	Phenomenological study	To explore the anti-SARS quarantine experience of patients in a hospital-based fever screening station.	Two themes emerged: external burden (bearing the uncomfortable surroundings, facing discrimination, and lacking in-person family support); and internal struggle (struggle with being quarantined, struggle with emotional turmoil, and struggle with possible SARS diagnosis).
Hao et al.[33]	Ten COVID-19 patients who received treatment in various hospitals (+10 age- and gender-matched psychiatric patients; and 10 healthy controls)	China (Chongqing)	Mixed-methods study	To examine the neuropsychiatric sequelae of acutely ill patients with COVID-19 infection who received treatment in hospital isolation wards during the COVID-19 pandemic.	COVID-19 + psychiatric patients > healthy controls: worry about their health, levels of depression, anxiety & stress. / COVID-19 patients > psychiatric patients + healthy controls: impulsivity & insomnia. / Half of COVID-19 had clinically significant symptoms of posttraumatic stress disorder.
					Three themes emerged: The emotions experienced by patients after COVID-19 infection (i.e., shock, fear, despair, hope, and boredom); the external factors that affected patients' mood (i.e., discrimination, medical expenses, care by healthcare workers); and coping and self-help behavior (i.e., distraction, problem-solving and online support).
Moradi et al.[27]	Eleven COVID-19 patients	Iran	van Manen's phenomenological method	To explore the experiences of patients with COVID-19 during care and quarantine.	Four themes emerged: characteristics of the experience, response to traumatic experience, deprivation, and confusion.
Shaban et al.[34]	Eleven COVID-19 patients admitted to a designated COVID-19 facility	Australia	Phenomenological approach (Heideggerian hermeneutical perspective)	To explore the lived experience and perceptions of patients in isolation with COVID-19 in an Australian healthcare setting.	Five themes emerged: Knowing about COVID-19, Planning for, and responding to, COVID-19, Being infected, Life in isolation and the room, and Post-discharge life. Within these, participants conveyed both positive and negative lived experiences of infection, isolation, and illness.
Cuttita[31]	1 COVID-19 patient	USA	Personal experience	To auto-ethnographically describe his experience of being hospitalized due COVID-19	Personal view

(*Continued*)

Table 2. Continued.

Author/s	Participants	Country	Design	Aims	Results
Guo et al.45	103 patients with COVID-19 who have been hospitalized	China (Shanghai)	Mixed-methods study (cross-sectional; descriptive phenomenological approach)	To understand how the infection of COVID-19 affects your mental status and daily-life."	Primary factors related to the patient's perception of stress: unexpectedness, loss of control (uncertainty), and sense of powerlessness. Qualitative data suggested unexpected factors were infection of COVID-19, the impact the disease has on people, the length of stay of the hospitalization. Uncertainty was due to the lack of information about the patient's ongoing changes of physical, the perceived paucity of support from health authorities, the unknown aspects of the COVID-19 disease. The sense of powerlessness caused by difficulties the patients could not solve, the inaccessibility to a healthcare facility, the side effects of treatment and morbidity and mortality associated with the disease, the stigma associated with COVID-19 that affected themselves, their family, and friends. Main post-traumatic symptoms: avoiding the internal and external clues of stressful experiences, blaming others, and having strong negative feelings, including fear, guilt, and helplessness. The main post-traumatic symptoms found among patients were avoiding the internal and external clues of stressful experiences, blaming others, and having strong negative feelings, including fear, guilt, and helplessness. Qualitative data suggested blaming of others were doctors, neighbors, health authorities. The feeling of fear was associated with uncertainty, isolation associated with being confined to an enclosed space, the worries concerning the consequence of the disease.
Yee et al.40	27 migrant workers diagnosed with COVID-19	Singapore	Phenomenological study	To understand migrant worker concerns and coping strategies during the COVID-19 pandemic to address these during the crisis and inform on comprehensive support needed after the crisis.	Three themes emerged: migrant worker concerns during COVID-19, coping during COVID-19 and priorities after COVID-19.

(*Continued*)

Table 2. Continued.

Author/s	Participants	Country	Design	Aims	Results
Sahoo et al.[39]	50 participants diagnosed with COVID-19	India	Cross-sectional study	To explore the experiences of patients during their hospital stay, who had significant distress when diagnosed with COVID-19 infection.	Initial emotional reaction to COVID positive status: shock (n = 36;72 %), feelings of sadness (n = 30;60 %), panic/ anxiety (n = 34;68 %) disbelief (n = 27; 54.0%), thoughts of "going to die" (n = 8; 16 %). Reaction to seeing the health care professionals in personal protective equipment (PPEs): like they were interacting with Aliens (24 %), astronauts/space scientists (14 %), or robots (22 %). Overall experience of staying in the COVID ward environment: as if staying in a prison/jail (34 %), as a bad dream (30 %), as torture (16 %), worse than jail (6%), relaxing (40 %), pleasant (38%), soothing (28 %), and homely (16 %). Emotions/feelings during hospital stay: anxiety (92 %), worried (96 %) and feeling isolated (90 %) for most or for almost all the days. Other: anger (66 %), irritability (76 %), fear of death (64 %), feeling disconnected (86 %), and hopeless (70 %). Coping methods: remembering God (66 %), talking to friends and family members over the phone (64 %) and praying to God (62 %)
Norouzadeh et al.[28]	16 ICU patients with COVID-19.	Iran	Qualitative study	To describe the experiences of patients with COVID-19 admitted to the intensive care units.	Three categories were identified: captured by a challenging incident with subcategories: perceived sudden and challenging death, fear of carelessness in overcrowding, worry about the family, and frustration with stigmatizing; the flourishing of life with subcategories: spiritual-awakening, resilience in the face of life challenges, promoting health behaviors, and striving for recovery; and honoring the blessings with subcategories: understanding the importance of nurses, realizing the value of family, and realizing the value of altruism.
Kumar et al.[46]	5 patients in isolation in the initial stage of the COVID-19 pandemic	India	Qualitative study	To explore the experiences of the patients in isolation and quarantine in the initial stage of the COVID-19 pandemic.	Five themes emerged: Having psychological impact, interpersonal impact, social impact, behavioral changes and impact on occupational aspects. The experience was predominantly unpleasant and characterized by anxiety, stigma, ostracization, guilt, and worry about the future.

(*Continued*)

Table 2. Continued.

Author/s	Participants	Country	Design	Aims	Results
Kürtüncü et al.[35]	18 hospitalized patients with COVID-19	Turkey	Qualitative study	To explore the experiences of COVID-19 patients in intensive care units and after discharge.	Four themes emerged: feelings about the illness and intensive care, psychological and physical damages, nurses' efforts, and the importance of care, and protecting health and life.
Sun et al.[52]	16 COVID-19 patients	China	Qualitative study	To explore the psychology of COVID-19 patients during hospitalization.	Five themes emerged: gradually developed into acceptance in the later stages; the major source of stress included the viral nature of the disease, quarantine measures, and concerns regarding the health of family members; Reactions of body and mind included disease stage-dependent emotional responses, excessive attention to symptoms, rumination, and changes in diet, sleep, and behavior; Supportive factors included psychological adjustments, medical care, and family and social support; the disease resulted in psychological growth and patients viewed problems with gratitude through the cherishing of life, family, bravery, and tenacity.
Jamili[38]	17 inpatients hospitalized with COVID-19.	Iran	Phenomenological study	To understand the lived experience of inpatients hospitalized with COVID-19.	Four themes were identified: denial of the disease, negative emotions upon arrival, perception of social and psychological support and post-discharge concerns and problems.
Liu and Liu[37]	14 hospitalized patients with COVID-19	China (Wuhan)	Descriptive phenomenological study	To describe experiences of hospitalized patients with COVID-19 following family cluster transmission of the infection and the meaning of these experiences for them.	Six themes emerged: the early outbreak phase and the later hospitalization phase. Early in the outbreak, patients experienced life imbalances between individual well-being and family responsibilities. While facing widespread prejudice and rejection, patients dealt with the heavy toll that the illness had left on their body and mind. After being hospitalized, patients described feelings of living with uncertainty, sadness, fear of death and concerns about family, while simultaneously hoping for a better life after recovery.

Along with loneliness came the anonymity that COVID has added to the health-care setting. This is embodied by every caregiver being required to wear a mask. In my 100 days of hospitalization, with upward of 100 clinicians looking over me, I saw only 4 faces. Two of these were nurses who broke the rules and wanted me to be able to recognize them if I ever saw them in public […]. Experience tells me that anonymity limits the intimacy of patient engagement and can fuel increased loneliness.[36(p1570)]

In the study with patients with MRSA,[35] even some years after the hospitalization, the feelings of guilt and shame remained.

Coping strategies

The second theme to emerge from the analysis concerned the coping strategies that participants employed in an attempt to deal with their situations. Here we identified two sub-themes reflecting adaptive and maladaptive coping mechanisms: finding hope and struggling with reality.

Finding hope. Some participants responded to the experience of a life-threatening illness by looking for hopeful outcomes. They engaged in a form of self-actualization with a focus on valuing and visualizing the positive, whether it be their eventual recovery or a closer spiritual connection. One of the most common coping strategies used in this respect was accepting their situation. In many cases, the initial shock of their diagnosis was followed by an attitude of acceptance that enabled patients to adopt a positive outlook with respect to isolation: “I will always encourage myself to think positively and try my best to adjust my mindset. An integral part of recovery is the mental attitude, so psychologists play a key role in the process.”[30](p9)

Many participants mentioned their faith and trust in God as being an important source of strength for coping with their circumstances.

> I think God gave me a time to [get] close to God. I recognize here there are very difficult patients, many many difficult patients. They have cancer, they have the problem with family and children. I think I am so thankful to God. I have just a short time experience for that, because I can understand others.[34](p1449)

Struggling with reality. Some patients found it hard to acknowledge that they had become infected with coronavirus, and this was associated with difficulties coping with the experience of isolation. These patients were reluctant to accept their diagnosis and the need for hospital admission and isolation: “You have COVID-19, they said. I couldn’t believe it. They wanted to put me in intensive care. I refused. They said if I don’t consent to being admitted, I’d be committing a crime.”[37](p7)

The growing sense of boredom and frustration made it difficult for these patients to cope with being isolated, and they struggled to get through each day without being overwhelmed by a sense of pessimism.

Connection/disconnection

Another core theme in patients’ experience of isolation was the impact it had on their sense of connectedness to loved ones (especially family), health care professionals, and to the outside world in general. Here there were three sub-themes: importance of human relationship, lack of humanized care, and being informed.

Importance of human relationship. The importance of human relationships and the presence of others was brought to the fore during the experience of isolation: “We not only needed physical care but, also, psychological and spiritual support because we were isolated; actually, in absolute isolation.”[32](p158)

And:

> I was so short of breath and of course I was lying alone and then she sat with me for an hour, really for an hour. Then she sat with me, just sat, I was lying down [on the bed] of course… I was short of breath, she said nothing else, just sat, just being there, that was already quite something. I liked that.[36](p6)

Especially for those participants who were hospitalized for long periods, in some cases months,[36] any direct contact with another person provided a sense of connection with reality, with humanity. Thus, after days of being cut off from the world, the daily contact with health professionals, even if they were in full personal protective equipment, became a positive experience. Many participants drew attention to the importance of humanized care, illustrated, for example, by staff showing empathy and compassion, taking the time to stop and talk, and attending to the little details of their care needs. Nurses in particular were seen as "angels"[30,37,38] and key vs in helping patients to feel less alone.

> The nurses who took care of me were fabulous; the respiratory therapist who added a humidifier to my oxygen intake helped me breathe easier; and the custodial staff who insisted on changing the sheets helped ground and humanize my time in the hospital. I am forever in their debt, as they cared for me and helped keep me alive.[39](p14)

Many participants also referred to the importance of being in touch with family, and being able to communicate with them through smartphones or tablets was a source of strength that helped them to cope with their feelings of loneliness.

> I am very grateful to my wife for her continued encouragement. During the period when I was staying in isolation, I felt lonely and sad. Due to changes in the environment, my state was worse than before, but she was always there encouraging me [this participant could contact his wife *via* remote communication].[30](p8)

Lack of humanized care. Some of the studies reviewed also reported negative experiences in the relationship with health care professionals. The lack of human and material resources in some settings left patients feeling that their needs went unattended, while others sensed there was a stigma attached to their condition. Impersonal care, a lack of empathy on the part of staff, and the impossibility of establishing a close relationship with them were all sources of distress among participants.

> I was very sick and I could barely walk. There was no one to help me and it felt like my world was falling apart. I was very thirsty but there was no one to bring me a glass of water or a cup of tea.[38](p3)

> I complained about the absence of nurses and the fact that they came to my bed only in emergencies. I thought the reason was that the medical staff feared me and the contagiousness of the disease and that they were negligent.[25](p334)

Being informed. Access to information, not only about their own condition but also about how the pandemic was unfolding on a global level, was a recurrent need for patients. Many of them sought information through the media and this allowed them to feel some sense of control over their situation and more connected to the outside world. However, the information they received was often very negative and did little to improve their experience of isolation. Many participants also mentioned the information they had been given about their diagnosis and prognosis, which in some cases was adequate and in others lacking. Patients who are well informed may feel more empowered, whereas the absence of information can produce uncertainty and helplessness.

> When I asked the physicians about my condition, their answers were nothing special, and were more or less the same. Actually, they would never answer my question. I wanted them to explain things to me in more detail and discuss with me what they knew, such as what condition I was in and whether I was going to live or die. I wanted to know my condition.[24](p155)

And, in the same study: “As I was already isolated, this lack of knowledge about my condition made me feel very helpless.”[32](p155)

Factors that influence the experience of isolation

The experience of isolation was explained through reference to two sets of factors, internal and external. The first relates to participants’ physical condition and the psychological impact of isolation, while the other concerns facility-related factors.

Personal impact. Isolation disrupted the lives of participants and had a strong impact on them personally. The clinical symptoms described in the studies reviewed ranged from mild to serious, including dyspnea, anorexia, fever, loss of smell and taste, and physical weakness, and dealing with them proved challenging and stressful for many patients: “I had a complete loss of appetite, nausea, shortness of breath, dry cough, high spiking fevers, severe muscle pain and stiffness, worsened fatigue, dizziness, and episodes of profuse sweating.”[39](p13)

Some participants also referred to the side effects of treatment or to symptoms of their illness that persisted beyond the acute phase. On a psychological/existential level, illness and isolation produced a series of losses: of normality, of health and wellbeing, of contact with loved ones and the outside world, and of control over one’s life and sense of time.

> I was hospitalized for 22 days. Each day seemed like a year to me. I found it so difficult to pass a day. Every day I waited for the doctor’s round and looked forward to hearing about my condition, whether it was getting better or worse.[24](p157)

Or: “We need to be in touch with the outside world […] when I was admitted, it seemed as if I had no choice in my daily life.”[24](p157)

> I never dreamt that I would be drawn into the dark depths of loneliness as a result of the extreme isolation that I experienced every day. Adding to my distress was the fact that, even under an optimum recovery time frame, I would be trapped in this situation for a very long time. Hopelessness and loneliness became a part of my day-to-day thinking, with little tangible progress.[36](p1570)

The emotional impact was especially strong among those whose experience was more extreme and negative, who looked death in the eye or who saw other patients die:

> The eyes of the patient next to me were open early in the night and he was awake. A few hours later, he died suddenly. He got short of breath and died before my eyes. I was terrified seeing him die and I thought ‘God who knows what will happen to us’. I do not know if I will be alive a few hours later or not. Perhaps I will not wake up in a few hours like this man. I had never felt death was so close.[40](p3)

Facility-related factors. Facility-related factors also affected participants’ experience of hospital isolation. In studies conducted in India and Singapore, one of the issues highlighted concerned insufficient economic and health resources for patient care,[33,41] and some participants spoke of the burden that their hospital stay implied: “Too cold during the night, sweltering and stuffy during the day, no food provided, no water to drink, many mosquitoes, and inconvenient toilet access."[31](p304)

By contrast, in settings where resources were good, hospitalized patients felt confident that their care needs would be met. The experience of isolation also varied depending on the nature of hospitalization: some patients spent days in an individual room in an ICU unit, whereas others were in shared spaces with limited resources and care.

Discussion

This review of 20 studies synthesizes findings about the experience of isolation on patients hospitalized during an infectious disease outbreak. The first theme to emerge from the analysis concerned feelings triggered by isolation. Although many participants recognized that isolation was a necessary safety measure to prevent their loved ones from becoming infected, it nonetheless had an important psychological impact. Some studies have found that the loneliness produced by isolation can lead to anxiety, depression, hopelessness, and feelings of guilt.[38,42] Shock, denial, sadness, and panic have been reported among patients who test positive for coronavirus. As Sahoo et al.[33] note, these types of reactions may be understood as a typical response to loss. A common emotion among participants in the studies we reviewed was fear. Studies that have explored the experience of isolation in non-medical settings (during home or institutional quarantine) have similarly documented feelings of fear due to uncertainty, suffering, and the possibility of death and of dying alone.[34,43] Fear of death increases susceptibility to anxiety and psychological disorders as a result of maladaptive strategies to cope with death anxiety.[14] There is also evidence to suggest that media reporting of pandemics creates a bleak picture which merely adds to patients' emotional difficulties.[34] By contrast, access to information that is realistic without being sensationalist can contribute to patients' well-being. Participants in the studies reviewed here commonly felt rejected. Similarly, other studies have shown that the stigma associated with infectious diseases such as Ebola or HIV in the 90's can have a highly negative impact on a person's identity and the possibility of their engaging in everyday activities and social relationships.[6,44] In studies with survivors of Ebola, a disease for which case fatality rates reached as high as 90%, the experience of abandonment, loneliness, and stigma is particularly notable.[5] The impact of stigma was also observable in the present review, insofar as participants in some studies were wary of telling others about their diagnosis for fear of being ostracized.[29,45] Silva et al.[46] have identified that stigma can be greater among vulnerable populations (immigrants, persona with lower levels of education, minority groups, etc.). In our present review, only Hao et al.[30] mention the fact that the association of China as the source of COVID-19 could transfer to a stigma toward those of Chinese ethnicity. In addition, studies from Bendjelloul,[27] Cava[47] y Mok[32] reported that unfavorable reactions from friends, work colleagues, and family members of those who contracted COVID-19 was conducive to perceived. In these cases, it can be seen how stigma, on the one hand, was a personal feeling that naturally surfaced from the inherent exclusion of hospital isolation, but also from relationships with others.

In the context of infectious diseases such as leprosy[48] or HIV[49] the associated social stigma could sometimes support aversion to healthcare environments by those affected. In our present review, the reasons given for not going the hospital were due to self-contempt and fear of infecting the hospital staff. In this sense, the moral judgment around how these illnesses are contracted influenced internalized beliefs that determined how the illness was experienced.

Por Finally, in relation to the first theme (feelings triggered by isolation), although numerous studies have found that there is a strong relationship between isolation[15,18,29] or the stigma of poor mental health outcomes with such as feelings of rejection, anxiety, depression and sadness, this review also shows that these factors could also co-exist with hope for a swift recovery, which may be possible because fatality rates for the diseases covered in our analysis are lower than in the case of Ebola.

The second theme to emerge, coping strategies, points to the potential for positive adjustment to the experience of hospital isolation in illness. It is interesting to note that although isolation led many patients to have thoughts and fears about dying, it was seen by some as an opportunity to reevaluate or change their outlook on what they valued most in life. The role of reported fears of death may explain such a strategy, as mortality salience has been argued to be a form of death preparation.[50] Older adults are shown to favor positive over negative interpretations of events,[51] which is thought to be a form of psychological maturity and adaptation over the lifespan in response to an increasing awareness of and preparation for death.[52] Therefore, patients who were able to focus on the positive over the negative may have become more aware and prepared for the possibility of death, which promoted psychological adaptation during isolation. Both positive and negative coping strategies found in this review are consistent with the study of stress and coping.[42] The self-blame or rumination on negative events that was present among patients who did not accept their circumstances are recognized to be maladaptive strategies linked to poorer well-being and depression,[53] whereas a focus on the positive is considered adaptive and even associated with reduced loneliness.[54] In the studies included, patients found hope by accepting their diagnosis and believing they would soon recover, by treating the situation as an opportunity for personal growth, and by trusting in God. The only study that focused on coping strategies[55] suggested that trusting professionals also promoted positive coping with the situation. Adaptive coping strategies can promote positive reappraisal, problem-solving and acceptance and finally reduce affective disorders.

Another issue that was brought to the fore by the experience of isolation was the importance of a connection to others and the outside world. For many participants, being able to contact family members, albeit remotely, and to share their experience was a source of strength. Only in one case was this kind of communication described as unhelpful, due to the worry and negativity of the relative with whom the patient had spoken.[30] The analysis of patient narratives also reveals the key role played by health professionals during isolation, especially nurses, through their ability to show empathy and compassion and to be attentive to patients' needs at all times. Some patients said that their experience in hospital had led them to appreciate the value of the nursing profession.

The personal circumstances of each participant meant that their experiences also differed in many ways. Some patients spent a considerable period in the ICU, whereas others were admitted with less severe symptoms to shared wards. In this context, some of the participants in the study by Jamili et al.[40] described seeing other patients die alongside them. In a study conducted in Wuhan, Liu and Liu[38] documented the traumatic impact that the death of loved ones had on families, the backdrop to which was the atmosphere of terror in the city. Other studies have similarly reported evidence of post-traumatic stress disorder (PTSD) in response to the crises resulting from epidemics.[7,34] Future studies should evaluate long-term psychological consequences and possible affective disorders (i.e. PTSD, depression or anxiety) after an infectious disease outbreak.

The experience of isolation was described both in terms of its personal impact, as an "internal struggle",[31] and also through reference to the "external burden"[31] produced by contextual factors. Some participants spoke of their boredom, of being unable to go about their daily life, and above all of being cut off from others and the outside world. One patient described how extreme isolation had drawn him into the "dark depths of loneliness"[36(p1570)], while another felt that "the world was falling apart"[40(p3)]. The fact that staff had to wear personal protective equipment also contributed to the dehumanizing nature of the experience. Despite these challenges, some participants used the time to reflect on their values in life, such that isolation became an opportunity for personal and spiritual growth.[33,39,56] As authors such as Paul[57] or Carel et al.[58] have pointed out, it is possible for illness to be a transformative experience through which people may learn and come to reappraise their values. Although only one of the studies in this review makes specific reference to resilience and tenacity, other authors have explored the role that these capacities may play in enabling people to adapt and overcome adversity.[26]

The sub-theme of facility-related factors may be unique to outbreaks. Although health care systems achieve varying success at the best of times, the rapid spread of infectious diseases such as COVID-19 can soon become overwhelming, revealing the limitations of individual facilities.[59] Preexisting structures and personal financial resources altered the overall interaction with the health care system for affected patients, highlighting the barriers that persist due to cultural norms. In general, health care delivery succeeds when it is acknowledged as a human right and universal priority, but even richer nations can vary in their perspectives of who is entitled to health as a fundamental right. It remains to be seen whether the current pandemic can serve as a lesson learned or if the literature is simply revealing a pattern of history repeating itself. Paradoxically, most studies revealed that having shared spaces resulted in feeling of lack of privacy and comfort, while in studies such as the one by Bouman et al.[55] carried out in the Netherlands, the authors question whether the fact of being in a single room, when it was not the patient's choice, can promote a greater feeling of loneliness. In this sense, it is striking how human contact can be appreciated or rejected according to preferences for care.

The results of this review highlight the crucial role that a person-centered model of care[12,60] may play in helping patients cope with the experience of isolation and prevent affective disorders during current or future infectious disease outbreaks. A key premise of this model is that patients are unique individuals who may be empowered by being included in decision making about their care, which also implies respecting their values and developing their strengths and abilities rather than their dependency. For participants in the studies we reviewed, the experience of isolation was characterized by feelings of loneliness, fear, and rejection, and in this context many of them referred to the importance of the human contact they had with staff, and the need they felt to remain informed about both their personal condition and the outside world. Although the circumstances produced by infectious disease outbreaks are clearly challenging, health systems should not lose sight of the importance of providing patients in isolation with humanized and person-centered care. As the person-centered guide states, we need to rethink the relationship between people and the services that provide their care for a better quality of life of our patients.

The majority of the studies included in this review involved patients who were placed in hospital isolation due to SARS and SARS-CoV-2. Consequently, it is unclear whether our findings regarding the impact of isolation are generalizable to patients in residential or other types of institutional quarantine (repurposed hotels), or to those who are isolated with other kinds of zoonotic viral infections, such as Ebola or H1N1. Another limitation of the present review is that the primary studies were carried out in the Far East, Middle East, South-East Asia, and Australia, with none pertaining to the Americas; the two reports originating from the USA were of an autoethnographic nature and presented first-person accounts of the hospitalization experience.

Conclusions

Patients with infectious diseases who are placed in hospital isolation commonly experience fear, stigma, and a sense of being deprived of both human contact and information about their condition and the outside world. The extent to which they are able to manage their isolation and loneliness depends, in part, on whether the coping strategies they use are adaptive or maladaptive. A person-centered care model is crucial for helping these patients cope with the impact of isolation.

Disclosure statement

No conflict of interest has been declared by the authors.

Funding

This work was supported by WeCare Chair: End-of-life care at the Universitat Internacional de Catalunya and ALTIMA, and Víctor Grífols i Lucas Foundation [BEC-2020-030].

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