Facing death alone and in isolation: A phenomenological study with survivors of COVID-19

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BACKGROUND

The COVID-19 pandemic is one of the greatest **human catastrophes** of the century so far. Not only did it lead to a tragic number of deaths but it also had a major psychological impact on people worldwide (Lee et al., 2005). Accordingly, numerous studies have highlighted the notable rise in **anxiety and depressive symptoms** associated with the outbreak (Lee et al., 2005; Li et al., 2020; Rajkumar, 2020; Wang et al., 2020; Xiao et al., 2020). During the first waves of COVID-19, when mortality rates were highest, large numbers of patients had to be **isolated**, and many of the most seriously ill **died alone** in hospital, without the company of loved ones. Isolation as an infection **control measure** may also be necessary in other scenarios, such as in the case of transplant patients or those infected with multi-drug resistant organisms (López Rivadeneira et al., 2021). The important challenge to patient **safety** posed by hospital-acquired infections, coupled with the severity of many of the pathogens involved, likewise calls for rapid isolation of patients to avoid further contagion (Jee, 2020). Given the ongoing need for isolation as an infection control measure, it is important to **understand the impact** it can have on patients, including the factors which may help them to cope with the **experience**.

To this end, the **aim** of the present qualitative study was **to explore the experiences of survivors of COVID-19 who had been isolated in a hospital setting during the pandemic.**

METHODS

DESIGN
A **qualitative study** involving **interpretative phenomenological** analysis (Smith et al., 2009) of in-depth **individual interviews** with survivors of COVID-19 who had been hospitalized and **isolated** during the first year of the pandemic.

SAMPLE
Inclusion criteria

- people with a confirmed diagnosis of COVID-19 whose condition had necessitated isolation in hospital during the first or second wave of the pandemic;
- age 18 years or older;
- able to read and understand Catalan or Spanish;
- good control of any residual symptoms at the time of the interview.

RIGOUR
Drawing on the criteria proposed by Lincoln and Guba (1985), we employed a series of strategies to ensure credibility, dependability and confirmability.

DATA COLLECTION
Semi-structured individual **interviews** via Zoom or Google Meet.

DATA ANALYSIS
We used ATLAS.ti 23 and the interpretative phenomenological method (Smith et al., 2009), a qualitative approach that seeks to explore and **understand** how individuals make sense of their lived experience in relation to a particular phenomenon.

Definition of the concepts of isolation, solitude and loneliness (adapted from Ettema et al., (2010)).

ISOLATION	The state of being physically separated from the world and from others with whom there is normally regular contact
SOLITUDE	Positive or constructive experience of being alone and separated from others
LONELINESS	Negative experience of being separated from others (mental and/or physical suffering due to being alone)

RESULTS

- Interviews were conducted with **20 individuals** and interviews lasted between **13 and 66 minutes**
- The patients had been admitted to **intensive care due to COVID-19** during the period between **March 2020 and January 2021**
- They ranged in age from **33 to 84 years**
- They had spent between **6 and 24 days** in hospital

THEMES

1 EXPERIENCE OF ISOLATION: BETWEEN LONELINESS AND SOLITUDE

SUB-THEMES

Isolation as a difficult challenge and existential threat

Our interviewees spoke of a variety of **symptoms** of varying severity that they experienced while alone in their room. Many of them referred to **having felt close to death**, and how the situation was made worse by not having their loved ones present. They spoke of feeling:

- **afraid and uncertain** about how things would develop
- **guilty** for making their family suffer
- **concerned** that they might have infected somebody else
- **outcasts** from society.

This meant that they **experienced isolation** as an **existential threat.**

Many of them referred to a sense of **loneliness** and the **fear of dying alone** without being able to say goodbye to loved ones or deal with unfinished business in life.

Loneliness or solitude as consequences of isolation

The inner experience of isolation differed depending on whether the predominant feeling was one of **loneliness** or **solitude**.

Loneliness: many of them spoke of having felt sad and disheartened:

- of the need for contact with others
- of missing their family and friends and
- of feeling abandoned by society.

Solitude: the same situation of isolation was experienced as having a positive side and they did not suffer simply because they were alone.

- time to reflect
- as an opportunity to distance themselves from routines, work and everyday concerns

2 MANAGING ISOLATION

Ineffective strategies: Distraction and seeking comfort in the relationship with health professionals

Strategies that were ineffective in helping them cope with their isolation and ill-health

1.Distraction techniques: while activities of this kind helped to break the silence or take their mind off things, they were not experienced as a genuine source of company.

- watching TV
- listening to the radio or music
- sleeping
- reading
- using a laptop

But simply trying to distract themselves and not think about their predicament did not ultimately relieve their suffering

2. Seeking comfort in the relationship with health professionals: patients' need for the company of others was often frustrated by the enormous difficulty of establishing any kind of meaningful contact with the staff who were caring for them.

Effective strategies: Acceptance, optimism and contact with family

Strategies that were effective in helping them cope with their isolation and ill-health

1.Acceptance of the situation: those ones reported feeling less impatient and more able to put their trust in the care they were receiving. their experience of isolation was characterized by a stronger sense of calm and security.

2. Optimism: whether in the form of trying to find positives in what they were going through, making the most of the time they had or striving to get well.

3. Contact with family: and the opportunity to receive support and affection and feel closer to family was, in their view, the thing that most helped them to cope during their time in hospital. (video calls)

3 ISOLATION AS A TRIGGER FOR CHANGE

A lasting **sadness**

Only a small minority of participants referred to a **lasting sense of sadness** following their time in hospital.

The predominant emotions:

- frustration
- denial
- hopelessness

Some of them had had to seek psychological help to **deal** with the negative impact that isolation and COVID had had on them.

Personal growth: Valuing what matters and reflecting on life

Their experience of loneliness and suffering had ultimately led them to **feel that they had grown as a person**.

This **personal growth** took from of:

- reconsidering priorities
- a stronger sense of what really matters in life
- an awareness of the importance of relationships with others

Some participants spoke of how **facing death alone and isolated** in hospital had made them:

- reflect on their **values**
- the **direction** their life was taking
- what really **mattered** to them
- feel **thankful** for their life
- recognize the importance of strong **relationships**
- feel the need to make the most of time with **family and friends**
- **show care and affection** toward those who matter most, because death can strike at any time.

CONCLUSIONS

- **Facing the possibility of death while isolated** in hospital often produces intense **loneliness** and **suffering**, yet for some people the experience can evoke a more positive sense of solitude and become an opportunity to reflect on life.
- Being able to **accept the situation** and adopt a more **optimistic** attitude towards recovery are strategies that appear to help patients **cope with isolation**, and maintaining contact with **family** through telephone or video calls is a key factor in this respect.
- The experience of illness and isolation can mark a **turning point in the lives** of patients, and while some may be left with a lasting sadness, many of those we interviewed said that it had led them to **reappraise their priorities and values in life.**
- **Health professionals have a key role** to play in helping isolated patients cope with the experience, minimizing its negative effects and, where possible, steering individuals towards personal growth.

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