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ARTICLE



Psychosocial impact of the COVID-19 outbreak and lockdown on Spanish oncological patients: a quantitative approach

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Asociación Española Contra el Cáncer

ABSTRACT

Background: This study analyses the levels of distress and related psychosocial factors among cancer patients during the Spanish lockdown due to COVID-19.

Methods: A total of 2,779 cancer patients took part in an observational and lateral study carried out between April 16, 2020 and April 25, 2020. An online questionnaire was distributed including distress-related variables, demographic variables, clinical variables about their oncological condition, socioeconomic variables and variables related to information management and social communication. Distress was measured according to the Kessler (K-6) scale, and its relationship with the remaining variables was analyzed by logistic regression.

Results: 33.5% of the patients yielded levels of clinical distress during lockdown. Younger patients and women yielded significantly higher levels of distress. High distress levels were generally associated with the following factors: trust in medical institutions; deterioration of the household's financial conditions; and media management of the information about the pandemic.

Conclusions: The lockdown triggered by COVID-19 increased distress among cancer patients, and this can be significantly related to a number of variables. Identifying distress, and said factors, at an early stage can help to develop mitigation strategies. Similarly, early detection can help to improve the way information is shared with patients, offer them support and resources and direct them to psychosocial services, increasing the patient's ability to return to normal after COVID-19.

KEYWORDS

Cancer; coronavirus; COVID-19; distress; lockdown; pandemic; psychological stress; Spain

Background

The infectious disease caused by coronavirus SARS-CoV-2 originated in December 2019 in China. The virus propagated worldwide at great speed. The illness arrived in Spain between February and March 2020. The

mounting number of infections drove the authorities to implement strict public health measures¹: a state of sanitary alarm was declared, and citizens were confined in their homes from March 14 to May 9 in an attempt to lower and control transmission.

These public health measures had a significant impact on the population both physically and mentally: uncertainty, insomnia, anger, fear of infection, increase in the consumption of alcohol and smoking, social isolation, post-traumatic stress disorder, anxiety, depression, somatization and a perception of bad health.² The psychological impact of confinement correlates moderate to high depression, anxiety and stress symptoms.^{3–5} High stress-related factors, anxiety and depression are particularly common among women, students, and those suffering COVID-19-like symptoms, fear of contagion in the family, and a poor perception of one's own health.^{6,7}

Cancer patients are particularly vulnerable to COVID-19, as they are generally over 55 years of age and, if they are receiving systemic treatment, could be immune supressed. In addition, the situation of sanitary alarm and the strict measures imposed by the authorities overwhelmed hospitals, delayed medical tests and treatments and the remote medical care, along with constant media coverage related to COVID, could have a direct effect on cancer patients. The quality of medical care is a direct factor impacting the quality of life of patients. Cancer patients that see their treatments interrupted present higher levels of anxiety and depression, and the fear that medical care will be poor in case of need is an important factor in terms of wellbeing and quality of life. Increased levels of distress, concern and fear of contagion were detected among cancer patients, especially younger patients, who are especially exposed to COVID-19 media coverage.

Distress is often measured to assess psychosocial sequelae among cancer patients. The National Comprehensive Cancer Network describes distress as "a multifactorial unpleasant experience of a psychological (i.e., cognitive, behavioural, emotional), social, spiritual, and/or physical nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment." Higher distress manifests in feelings of fear, vulnerability and sadness, and severe cases can lead to depression and anxiety. The negative consequences of distress have led cancer-related organizations to consider this factor as a core variable in cancer treatments. Distress has been associated with lower survival levels, 16 a poorer quality of life 17 and less satisfaction with medical care. 18

Similarly, distress has been positively correlated with other variables such as sex (women), age (18-39 years) and the financial burden of cancer. ^{19,20} Cancer patients tend to be financially more vulnerable, leading to less quality of life. ²¹ Unemployment and financial insecurity are linked to psychological problems, ²² especially depression. ²³ Young cancer patients are

particularly vulnerable to this situation, and present higher levels of finance-related distress^{19,24} and more difficulties to find a job or improve their training.²⁵ These can be compounded with cancer-related disabilities or job redundancy. Financial insecurity is a direct factor in the decrease in the levels of wellbeing.²⁶

Evidence of the impact of the SARS-CoV-2-triggered lockdown on cancer patients is still scarce, and although several studies that address this emotional impact have been published, on none of these studies deal with the case posed by Spain. This study aims to identify the psychosocial impact of the pandemic-related lockdown on cancer patients, and thus make a first exploratory and empirical approximation to distress levels and related factors in such a vulnerable group.

Methods

Research design

The study is conceived as a first, eminently empirical exploration, through a web-based self-administered questionnaire; respondents were recruited by river sampling²⁷ after the study had been advertised through different cancer patients groups, social media groups and mailing lists. Although the sampling strategy suffers from the usual problems associated with self-sampling (i.e. uneven coverage), it is the only way to reach hard-to-access groups for which censuses are lacking, such as cancer patients.²⁷ Response time was on average 10 minutes, and 69% of respondents answered all questions (incomplete questionnaires were removed from the sample). Data were collected April 16 to April 25, 2020.

Participants

The final sample encompassed 2,779 diagnosed cancer patients (their inclusion was controlled through initial disqualifying questions about their diagnosis), living in Spain: 86.9% of respondents were women; 40.2% were over 54 years of age; 39.2% held university degrees; and 15.2% were employed at the time of responding to the questionnaire (30% were retired; 14.3% were unemployed, and 28.6% were on medical leave).

Measures

Kessler K-6 psychological distress scale

For the evaluation of our study's main variable we used the Spanish translation of the Kessler K-6 scale. 28,30 This scale measures the frequency with which individuals have presented nonspecific symptoms of psychological discomfort within the last 30-day period (all of which, in the case at hand,

fell within the lockdown period). The questionnaire is easy to answer and has been used in multiple studies, and it has also been specifically validated for the Spanish case. The questionnaire was selected because it has proven its value and reliability for the screening of severe psychological conditions, and specifically major depression and generalized anxiety, based on DSM-IV's mental disorder diagnostic criteria (DSM-IV)^{31,56} and DSM-V's. Selected as a 5-point Likert scale from 0 (never) to 4 (always). The aggregate score goes from 0 and 24. Any score above 13 is considered indicative of severe psychological conditions. The scale is regarded as having good sensitivity and specificity for the prediction of anxiety and depression disorders. In our study, the scale yielded a Cronbach Alpha score of 0.875, and a score of 0.865 in the Kaiser-Meyer-Olkin test after an exploratory factor analysis with a single factor with values above 1; the scale presented high internal consistency levels.

Other variables, based on prior qualitative studies by the authors, were incorporated to the questionnaire, as were aspects outlined by previous studies that address the psychological impact of pandemic outbreaks, such as the one caused in Canada by SARS-CoV (SARS),³⁶ H1N1 and Middle East Respiratory Syndrome (MERS).³⁷ The questionnaire was also examined by a group of experts specialized in treating oncological patients.

Socio-demographic characteristics

In addition to their sex and age, the participants provided information about their level of education, professional status, religious beliefs and the composition of their household during lockdown (people with whom the respondent lived).

Health condition and oncological condition

The respondents were asked about aspects related to the diagnosis and treatment of their illness. Specifically, they were asked what type of cancer they were suffering, time since cancer diagnosis, the stage of the illness, the oncological treatment undergone, and their situation with regard to the last treatment period.

They were also asked whether they had had any tests or treatments delayed as a result of the health emergency.

Income

Respondents were asked about monthly household income as well as about possible changes in the household's financial status as a result of the COVID-19 pandemic.

COVID-19 diagnosis or symptoms

Respondents were asked whether they, a relative or a friend had been diagnosed with COVID-19. Finally, they were asked whether they were living with the COVID-19-diagnosed person.

Attitude toward coronavirus

This section encompassed the attitudinal variables that are regarded in existing qualitative studies as most relevant predictors of psychological conditions: concern about the health crisis; fear of contagion (including that of a friend or relative); self-perceived mindset when facing total lockdown; anxiety derived from seeking information about COVID-19; and the effects of everyday exposure to this information. All these variables were measured on a four-point scale from 1 (totally disagree) to 4 (totally agree).

Perception about the measures adopted to face the health crisis caused by COVID-19

This section assessed the degree of agreement with the measures undertaken to face the crisis, as well as the respondent's trust in political and healthcare institutions. Answers were presented on a 4-point scale from 1 (totally disagree) to 4 (totally agree). The questions were as follows: "I think that cancer patients are receiving appropriate medical care during this crisis;" "I fully trust the information that my doctors are giving me;" "I think that a total lockdown is a good measure to ensure the safety of the population."

Data analysis

Statistical analysis was undertaken with IBM SPSS v22 software. Descriptive analysis was undertaken to establish which of the questionnaire's variables were statistically significant (χ 2, p < 0.05) based on the number of patients above the K-6 threshold of psychological discomfort (K-6 > 12).

Afterwards, in order to check which variables are most valuable to predict patients entering levels of clinical condition, binary logistic regression was used, taking the K-6 scale score as a dependent variable (dividing patients in two groups, above and below the cutoff point defined above) and all variables that had yielded significant differences in the previous operation as independent variables. Forward stepwise regression analysis was used for the logistic regression, following likelihood reduction criteria. The model has a good level of statistical significance and a good fit (Nagelkerke's $R^2 = 0.268$; % correctly characterized cases = 74.6).

Table 1. Logistic regression model obtained.

	Coefic	Typical			Probability
Variable	В	Error	Wald	Exp (B)	increase
COPING WITH LOCKDOWN CONDITIONS	-1.712	0.137	156,607	0.181	-26.40%
SHIFT TO ONLINE APPOINTMENTS WITH	0.682	0.106	41,290	1.978	16.86%
PSYCHOLOGISTS AND SOCIAL WORKERS					
TRUST IN THE INFORMATION PROVIDED BY	-0.671	0.143	22.101	0.511	-15.42%
THEIR DOCTORS					
GENDER (Male)	-0.439	0.156	7.936	0.645	-10.97%
MONTHLY INCOME (>1,800 euros)	-0.437	0.110	15.787	0.646	-10.85%
"I cannot help but constantly watch the news on	0.423	0.112	14.270	1.526	10.44%
television and in newspapers about the					
coronavirus crisis/COVID-19"					
AGE (\geq 45 years)	-0.419	0.118	12.542	0.658	-10.19%
HOUSEHOLDS WHOSE FINANCIAL CONDITIONS	0.408	0.130	9.792	1.503	10.18%
HAVE DETERIORATED					
DIFFICULTS ACCESSING PSYCHOLOGICAL AND	0.402	0.139	8.327	1.495	10.04%
SOCIAL SUPPORT SERVICES DURING					
THE LOCKDOWN					
FEAR OF CONTAGION	0.380	0.180	4.458	1.462	9.24%
"The coronavirus pandemic has been practically	0.363	0.109	11.083	1.438	9.00%
my only topic of conversation these days."					
CANCER STAGING (Localised or palliative)	0.313	0.102	9.338	1.367	7.78%
DELAYS IN APPOINTMENTS FOR SCREENINGS AND	0.247	0.106	5.451	1.280	6.16%
DIAGNOSTIC TESTS					
RELIGION (Catholic)	0.232	0.104	4.961	1.261	5.78%
Constant	0.333	0.267	1.559	1.395	

The model is presented in Table 1, along with B slope coefficients, Wald test (p < 0.05 in all cases) and the exponents or change in the odds ratios. In order to facilitate the interpretation of the model, the increase in likelihood was calculated for all variables.³⁸

Results

33.5% of patients yield scores above the cutoff point defined above in the K-6 scale (\geq 13), suggestive of a pathological state of anxiety or depression. At the time the survey was undertaken, only 1.5% of patients had been diagnosed with COVID-19, although a further 4.9% believed that they had or had had COVID-19-like symptoms.

18% of patients had seen their household financial situation deteriorate seriously or very seriously from the beginning of lockdown. 15.5% stated not to be coping well with lockdown; 88.8% stated to be very afraid of contagion (of themselves or friends or family); and 95.9% claimed to be concerned or very concerned about the health crisis in general.

With regard to their relationship with the media, 52.6% claimed not to be able to stop searching for news about COVID-19, and for 52.5% this had been their only topic of conversation for days.

Concerning medical care, 23.1% claimed not to think that cancer patients were receiving adequate medical care, and 13.1% mistrusted the information provided by their doctors; 5.1% did not think that the lockdown was an effective measure against the pandemic.

With regard to the effect of lockdown on cancer treatment, 34.5% claimed to have had tests delayed and 10.5% to have had their treatments delayed; 41.3% were forced to shift to online medical appointments.

Five groups of variables that had a especially significant effect on patient distress (Table 1) and are valuable predictors of clinical conditions: lockdown- and fear of contagion-related variables; medical and psychological care; management of information and trust in political and health authorities; factors related to their financial situation; and, variables related to the patient's socio-demographic features and/or their pathology.

Lockdown and fear of contagion

The variable that better predicts nonspecific psychological discomfort have to do with lockdown conditions. Cancer patients who claim to be facing the government-imposed lockdown in good spirits see their risk of suffering from clinical discomfort reduced by 26.4% (OR 0.181). Much less valuable in terms of prediction is fear of contagion (including that of friends and relatives), with the likelihood of psychological discomfort increasing by 9.24% (OR 1.462).

Access to sanitary and psychological services

The next item in the model are variables related to the shift to online appointments with psychologists and social workers (+16.86%, OR 1.978) and with perceived difficulties to access psychological care services (+10.04%, OR 1.495). Both variables are associated with the patients' perception of needing psychological support. Concerning healthcare, the model only reflects the possibility of having tests delayed, which increases the risk of suffering clinical distress by 6.16% (OR 1.28); delays in treatments and a shift in the format of medical consultations, etc. do not feature in the model.

Management of information and trust in public institutions

It is attested that patients that trust the information provided by their doctors see the risk of suffering clinical distress decrease by 15.42% (OR 0.511). Conversely, those patients who have not been able to manage the flow of information about the pandemic adequately ("I cannot stop watching TV news and newspaper stories about the coronavirus crisis") and those for whom the pandemic is the only topic of conversation see their risk of suffering clinical distress by 10.44% (OR 1.526) and 9% (OR 1.438), respectively.

Socio-demographic characteristics of the patient

The likelihood of clinical distress is lower in men -10.97% (OR 0.645) – and significantly higher among younger patients: patients who are above 45 years are 10.19% (OR 0.658) less likely to be above the cutoff point in the K-6 scale. No significant correlation was found between age and gender and the rest of the predictors. Patients who are undergoing treatment at the time of the survey are 7.78% (OR 1.387) more likely to suffer clinical distress than those who are not. Finally, patients who declare themselves Catholic are 5.78% (OR 1.261) more likely to suffer clinical distress than those declaring to be agnostic, atheists and followers of other religions.

Financial situation

Finally, the regression model includes two items that refer to the economic situation of the patients' households, both of which have a high predictive value. Patients whose income is above €1,800 (or \$2.214)/month (the situation of the 60% of the patients) see their risk of suffering from clinical distress reduced by 10.85% (OR 0,646). Conversely, households whose financial conditions have deteriorated significantly are 10.18% (OR 1.503) more likely to be above the cutoff point in the K-6 scale.

Discussion

The results of this study are a first approximation to the psychosocial impact of COVID-19-triggered lockdown among cancer patients. Focusing on psychological distress,³⁹ we can argue that cancer patients have been negatively affected by lockdown, which has caused severe distress, as the results clearly show. This increase in the levels of psychological distress could be explained by the increasingly difficult access to psychosocial care, as this is a population group that is specially reliant on these services.

It is worth stressing that concern for the pandemic among cancer patients is clearly higher than among the population in general; 66.5% of respondents claim to be very concerned, versus 59% overall, according to CIS [Spanish Center for Sociological Research] data, 40 or 45% according to a study by UCM [Complutense University of Madrid]. 7 The study also indicates that 84.5% of respondents are not coping well with lockdown. This concern may be especially significant in cancer patients and their levels of distress. Three factors could be at play here, as pointed out by a study published by Cancer Care Europe (2016): first, a greater perception of the risks of contagion (or an overestimation of risk, especially among cancer survivors); second, fear of medical complications; and third, fear of the health crisis affecting the system's ability to provide optimal care.

Young cancer patients present significantly higher levels of distress. This agrees with the study published by the Milan National Cancer Institute, 11 which shows that young cancer patients perceive themselves as more at risk of suffering severe complications in case of COVID-19 contagion. This could reflect that young adult patients see the current crisis as a threat to their life project, which is still in construction. This could also be related to excessive exposure to the media and social media; according to Gao et al.⁴¹ young people who are especially active in social media present greater levels of anxiety and depression.

Excess information has not helped cancer patients to cope with the crisis. Our study finds a high correlation between the inability to disengage from information flows and high levels of distress. In the same vein, a team from the University of California⁴² have argued that overexposure to the news can increase the sensation of risk, leading to long-term sequelae. Previous studies about lockdown situations have reached similar conclusions, showing that information and social communication can contribute to increase stress levels.⁴³

This variable is related with a lack of trust in the information provided by health authorities, 44-49 which in our model also appears as an important predictor variable. These data are especially relevant in relation to the perception of the measures taken to deal with the pandemic and its emotional impact.⁵⁰ However, it is worth noting that, despite the difficulties, the results suggest that cancer patients have in general a good opinion of the medical care received during the pandemic, which thus stands as a good predictor of emotional wellbeing.

Delays in diagnostic tests and medical treatments as a result of hospitals being overwhelmed by the pandemic is another significant predictor variable of distress. Patients who have suffered delays, regardless of the stage of the illness in which they are, present higher levels of distress, probably as a result of the fear to the pandemic interfering with their treatment.⁵¹

Finally, the economic crisis resulting from the situation of sanitary alarm and lockdown is another clear factor of distress. Often, cancer patients lose their jobs, either permanently or temporarily, and many undergo periods of financial instability, a situation aggravated by the current crisis; a large number of patients claim to have seen the financial position of their households deteriorate, in agreement with previous studies. 22,23,52,53 There is little doubt that this will have long-term effects, especially as a result of the protracted economic crisis caused by COVID-19, which will compound the sensation of psychological vulnerability of cancer patients.

Limitations

As noted, this study is only a first exploration of the issue, and is eminently empirical in nature. The myriad psychosocial variables at play in the

current crisis, and the special shape which this crisis has taken in countries such as Spain, make the results difficult to extrapolate to other countries.

In addition, difficulties to access cancer patients and the limitations resulting for the type of survey used, which greatly constrains the space available for the introduction of different scales, has forced us to restrict analytically complex dimensions to 1-item questions.

However, we think that this is a useful first approximation to the psychological condition of cancer patients during lockdown in Spain. Its results will aid us to delve further into variables that predict distress from other methodological perspectives.

Conclusions

The results of this study suggest that the imposition of lockdown and other related measures require a closer monitoring of vulnerable groups such as cancer patients, whose illness-related distress is only compounded by the current circumstances. Therefore, should healthcare systems have to face the continuity or resurgence of coronavirus or a similar contagious disease, the issues outlined by this study should be taken into consideration, especially with regard to cancer patients.

Detection of distress among cancer patients is essential, especially among those who present risk factors such as the ones identified in this study: young; female; living in a family with children during lockdown; unemployed or with a household income below €1,100/month; overexposed to information; within the first year after cancer diagnosis; with impending medical appointments.

Implications for psychosocial oncology

Results of studies addressing the mental impact of measures adopted to face the COVID-19 pandemic could help social-health authorities to better monitor and provide better psychological care to cancer patients. As healthcare professionals, we should demand that this population group is provided with appropriate care (both in person and online). We recommend the implementation of relatively simple measures such as Distress Thermometers⁵⁴ or the Edmonton Symptom Assessment System,⁵⁵ and their application by telematics channels.

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No potential conflict of interest was reported by the authors.

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