

# Living with cancer in the COVID-19 pandemic: An Italian survey on self-isolation at home

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## Research Article

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# Abstract

**Objective:** To investigate the perception of self-isolation at home in patients with cancer during the lockdown period because of the COVID-19 outbreak in Italy.

**Methods:** A cross-sectional descriptive study was conducted through an online survey from March 29<sup>th</sup> to May 3<sup>rd</sup>, 2020. Perception of self-isolation was assessed in patients with cancer during quarantine at home using the ISOLA scale, after evaluation of its psychometric properties. Content analysis was used to analyse two open-ended questions.

**Results:** Participants were 195 adult patients with cancer (female = 76%; mean age = 50.3 ± 11.2; haematological malignancy = 51.3%). They reported moderate isolation-related suffering (M = 2.64 ± 0.81), problems in the relationship with others (M = 3.31 ± 1.13), and difficulties in the relationship with oneself (M = 3.14 ± 1.06). Patients who experienced significantly more social problems were the older ones, with lower education, and living without minor children. Overall, four main categories emerged from the qualitative content analysis: 1) Lack of freedom and social life, 2) Uncertainty and worries, 3) Feeling supported, and 4) Dealing with isolation.

**Conclusion:** Living with cancer in the COVID-19 pandemic was often perceived as an isolating experience, primarily in terms of detachment from loved ones.

## Introduction

After China (Wang et al., 2020), Italy has been the second country to be involved in the COVID-19 pandemic and one with the highest death toll (ISS, 2020; Remuzzi & Remuzzi, 2020). The World Health Organization (WHO) recommended preventive actions to reduce transmission of the SARS-CoV-2 virus, including appropriate hand hygiene and social distancing (WHO, 2020). On March 9<sup>th</sup>, the Italian Government implemented extraordinary measures to contain the spread of COVID-19 (Lazzerini & Putoto, 2020). Lockdown was enforced on all citizens, except for necessity, work in essential services, and health circumstances (Sjödin, Wilder-Smith, Osman, Farooq, & Rocklöv, 2020). More restrictive containment measures, the so-called 'Phase One' of the COVID-19 emergency plan, were implemented from March 9<sup>th</sup> until May 4<sup>th</sup> (Italian Ministry of Health, 2020). This has required quarantine at home and a substantial behavioural change in terms of hygiene and social practices within the community.

Among people at higher risk, cancer patients were indicated as more vulnerable to both the SARS-CoV-2 infection (Richardson et al., 2020; Yu, Ouyang, Chua, & Xie, 2020) and its complications (Emami, Javanmardi, Pirbonyeh, & Akbari, 2020; Liang et al., 2020; Onder, Rezza, & Brusaferro, 2020). Thus, the request to stay at home in self-isolation shall be read not only as a restrictive measure but also as a protective recommendation (ESMO, 2020; NCCN, 2020). Despite efforts of oncology clinicians in providing cancer treatment safely in the face of uncertainty and rapid change (Cinar et al., 2020; Combs et al., 2020; Meattini et al., 2020; Russano, Citarella, Vincenzi, Tonini, & Santini, 2020; Trapani, Marra, &

Curigliano, 2020; Ueda et al., 2020; Valenza et al., 2020), cancer patients and survivors had to face several challenges in accessing healthcare services, especially those travelling to receive care (ACV, 2020; Chan et al., 2020).

In the context of grave threats to their physical and mental health (Stefana, Youngstrom, Hopwood, & Dakanalis, 2020; Vigo et al., 2020), people living with cancer had to cope with several stressors including fear of SARS-CoV-2 infection, inadequate supplies, scarcity of information, financial loss, stigma, and constrained freedom (Brooks et al., 2020). Thus, the psychological impact of mass quarantine in the context of a pandemic, in terms of stress, anxiety, depression, and poor sleep quality (Casagrande, Favieri, Tambelli, & Forte, 2020; Rubin & Wessely, 2020; Wang et al., 2020), as well as isolation-related loneliness (Brooks et al., 2020; Hawryluck et al., 2004), could be even worse for cancer patients, who need emotional support from others to alleviate their feelings of loneliness and maintain mental health (Adams et al., 2016; Secinti et al., 2019). Although the restrictive measures have been essential to reduce the outbreak of the virus, they may have severe psychosocial consequences in people living with cancer.

When isolation is forced on cancer patients to protect them from infection, even though it is often experienced as a shield for an effective defence (Biagioli et al., 2017), it can imply psychological suffering (Biagioli, Piredda, Mauroni, Alvaro, & De Marinis, 2016). Similarly, stay-at-home ordinances have been proven effective to contain the spread of the novel coronavirus, but prolonged self-isolation at home may lead to substantial negative implications (Brooks et al., 2020), which may jeopardize people's health (Lippi, Henry, Bovo, & Sanchis-Gomar, 2020). Thus, describing how people living with cancer experienced self-isolation at home during the lockdown in Italy may help health professionals get a more complete picture of the cancer experience during the COVID-19 emergency from the patient perspective. Therefore, this study aimed to investigate the perception of self-isolation at home in people living with cancer during the mass-quarantine in Italy for COVID-19.

## Methods

### Design and Participants

This is a cross-sectional descriptive study of the cancer patients' perceptions of self-isolation at home in the context of the COVID-19 emergency. Data were collected through an online survey from 29th March to 3rd May 2020, which corresponds to 'Phase One' of the lockdown in Italy. Participants were adult cancer patients ( $\geq 18$  years) in quarantine at home because of the COVID-19 outbreak in Italy, regardless of the stage of disease and treatment phase.

### Instruments

Perceive isolation was measured using the ISOLA scale (Biagioli et al., 2019a). This is a 14-item self-report questionnaire to assess the perception of being in protective isolation. It was originally developed to collect the isolation experiences of patients with haematological malignancies undergoing haematopoietic stem cell transplantation (HSCT). Its construct validity was tested through exploratory

factor analysis (EFA) and three dimensions were found: isolation-related suffering (F1), problems in the relationship with others (F2), and difficulties in the relationship with oneself (F3) (Biagioli et al., 2019a). Participants are asked to indicate the extent to which they feel isolated on a scale ranging from 1 (not at all) to 5 (completely). Higher scores in each of the three dimensions indicate a more negative experience. At the end of the ISOLA scale, two open-ended questions were posed: 'What is helping you in this isolating situation?' and 'What is the worst aspect of this isolating condition for you?'

Socio-demographic information and cancer diagnosis were also collected, together with data about the characteristics of their stay at home. Participants were asked to describe the changes in the relationships with their family members, their beliefs about their risk for SARS-CoV-2 infection and potential complications, and the impact on their disease using multiple-choice items.

### **Procedure and Ethical Aspects**

People living with cancer were invited to participate in the study while they were self-isolated at home because of the national lockdown, which was imposed by the Italian government on March 9<sup>th</sup>, confirmed on March 17<sup>th</sup> with additional restrictions mandating the temporary closure of non-essential shops and closure of the parks, and relaxed on May 4<sup>th</sup>, 2020, in response to the growing COVID-19 outbreak in the country. Potential participants were contacted via social groups like Facebook or patient associations and asked to fill in the survey throughout a link. A snowball sample was generated among cancer patients.

The study purposes, procedures, and data collection were clearly explained to potential participants in the text accompanying the link to the survey. The first part of the survey informed that participation was voluntary, and completion included consent to using data for scientific purposes. Data were collected and held anonymously according to International Ethical Guidelines and Principles for research (CIOMS, 2016). The study was approved by the scientific committee of the Italian Association of Cancer Nurses (AIIAO).

### **Data Analysis**

Study variables were described using descriptive statistics (frequency, percentage, range, median, mean, and Standard Deviation [SD]). The construct validity of the ISOLA scale in the context of being isolated at home, which was hypothesized to be similar to the original version (Biagioli et al., 2019a), was tested through Confirmatory Factorial Analysis (CFA) using a robust estimator (MLr). The following indices were considered to evaluate the fit of the model: chi-square ( $\chi^2$ ), the Root Mean Square Error of Approximation (RMSEA; values  $\leq .06$  indicate a good fit), the Comparative Fit Index (CFI; values  $\geq .90$  indicate a good fit), the Tucker and Lewis Index (TLI; values  $\geq .90$  indicate a good fit), and the Standardised Root Mean Square Residual (SRMR; values  $\leq .08$  indicate a good fit). Reliability was tested using Cronbach's alpha (internal consistency).

ISOLA scale scores were calculated as means (SD). Univariate analysis of variance (ANOVA) and *t*-tests were used to identify any difference in the mean scores for socio-demographic and clinical variables. Pearson correlation was employed to investigate associations between continuous variables. Statistical analyses were performed using SPSS 22.00 (IBM Corp, Chicago) and Mplus 6.1 (Muthèn & Muthèn Los Angeles, California 2012).

To analyse the two open-ended questions at the end of the ISOLA scale, we used a descriptive qualitative approach based on inductive qualitative content analysis (Vaismoradi, Turunen, & Bondas, 2013). The coding process was systematic and sentence responses from each question constituted the *meaning units*. Two researchers first read and discussed each meaning unit and then assigned units with common sense to preliminary sub-categories. To generate overarching commonalities, subcategories were grouped into broad categories, which were exhaustive and mutually exclusive. Consensus with two additional expert researchers was gained to ensure trustworthiness.

## Results

### Participant Characteristics

Overall, 195 patients completed the survey. Their socio-demographic and clinical characteristics are reported in Table 1. They were mainly female ( $n = 148, 75.9\%$ ), with a mean age of 50.3 (SD = 11.2, range = 25-78) years and a high level of education (university or postgraduate = 66, 34%). Patients had been diagnosed with haematological malignancies ( $n = 100, 51.3\%$ ), breast cancer ( $n = 51, 26.2\%$ ), or another solid tumour ( $n = 44, 22.6\%$ ). Only 9% were living alone and 39.1% were living with children younger than 18 years (Table 2).

### Participants' Opinion, Behaviour, and Experiences during Self-isolation

Many of them ( $n = 77, 39.5\%$ ) were in self-isolation for more than 6 weeks. Most participants reported never/rarely ( $n = 156, 80.4\%$ ) leave their house during 'Phase One' quarantine (Table 2). Changes in the relationships with their family members occurred in 45.1% participants, including avoiding kisses and hugs ( $n = 61, 31.9\%$ ) and practising social distance ( $n = 23, 12.0\%$ ). Many participants believed to be at higher risk for SARS-CoV-2 infection than the general population ( $n = 105, 53.8\%$ ) and were completely/very afraid to suffer from severe consequences in case of infection due to their cancer ( $n = 99, 50.8\%$ ). Some of them ( $n = 47, 24.5\%$ ) were also very much/completely afraid that their cancer care would become less important and that would negatively impact their prognosis ( $n = 26, 19.1\%$ ). About 29% ( $n = 56$ ) participants reported that their health status was not under control, mainly because they were not monitoring their cancer condition through clinical exams ( $n = 17, 8.7\%$ ) and/or attending outpatient visits ( $n = 41, 21\%$ ). Besides, many of them ( $n = 72, 37.3\%$ ) were very much/completely afraid of going to the hospital because of the COVID-19 outbreak.

### ISOLA scale

Mean scores of each item of the ISOLA scale showed that participants considered a relevant problem not being able to stay close to their loved ones and they felt quite detached from them while missing enough contact with the outside world (Table 3). The three original dimensions F1 '*Isolation-related suffering*', F2 '*Relationship with others*', and F3 '*Relationship with oneself*' were confirmed at CFA, except for item 12 which loaded on F1 rather than on F3 (Figure 1). The covariance between residuals of item 9 '*I feel cut off from the world*' and item 11 '*I feel imprisoned*' was specified in the model following similarity in meaning and modification indices. The fit indexes were satisfactory:  $\chi^2$  (df: 73) = 144.69,  $p < 0.001$ ; RMSEA = 0.071 (90% CI = 0.054-0.088); CFI = 0.926; TLI = 0.908; SRMR = 0.057. Factors loadings were all significant and  $> 0.3$ . Cronbach's alpha for F1 was 0.88, it was 0.83 for F2, and it was 0.70 for F3. The mean scores were 2.64 (SD = 0.81) for isolation-related suffering, 3.31 (SD = 1.13) for problems in the relationship with others, and 3.14 (SD = 1.06) for difficulties in the relationship with oneself.

## Associations

F2 was significantly negatively correlated with the level of education ( $r = -.249$ ,  $p < .001$ ): the less education had the participants, the more they experienced problems in the relationship with others. Also, older participants reported more problems in the relationship with others, as F2 was positively correlated with age ( $r = .249$ ,  $p < .001$ ). At ANOVA, participants living with children younger than 18 years reported lower social problems than others ( $p = .04$ ).

## Qualitative data

Overall, four main categories emerged from qualitative content analysis (Table 4). Two refer to the worst aspect of isolation: 1) *Lack of freedom and social life*, and 2) *Uncertainty and worries*. The other two refer to what was helpful: 3) *Feeling supported*, and 4) *Dealing with isolation*.

***Lack of freedom and social life.*** The lack of freedom and social life was described in terms of deprivation of freedom and mobility, detachment from family members, lack of social interactions, and missing everyday life. One of the worst aspects of self-isolation was expressed by patients as missing freedom and the possibility to move around, so that they felt '*in prison*' (P141). Not only the absence of other family members who were not living with them was particularly distressing, but also the impossibility to have physical contact with those close to them, such as their children, was expressed as depleting: '*His hugs are my strength, my oxygen*' (P16). Moreover, participants reported that their social interactions had vanished: '*Not having a social life anymore*' (P104). They also missed their everyday life, their routine, including their job, which contributed to their conception of normality. This was expressed as complicating a delicate situation: '*I miss my usual life, already partially compromised by the disease last year*' (P116).

***Uncertainty and worries.*** Uncertainty about an unknown future and worries about infection, economic difficulties, and the health system were expressed predominantly by participants. Uncertainty was described as an endless tunnel and commonly manifested for the future situation: '*how and when it will end*' (P34). One of the participants' biggest concerns was the fear of getting COVID-19, which was

enhanced by their cancer diagnosis: *'the fear of infection because of my health condition (P39)'*. Worries emerged, also, relatively to *'the economic aspect' (P45)* and, more importantly, to the continuation of cancer care *'anxiety about not being able to go the hospital (P18)'*.

**Feeling supported.** Feeling supported meant closeness of family and pets, self-help/mutual support, and hope and spirituality. In particular, participants acknowledged the value of having their family members close to them during self-isolation, especially their children, and to find support in their partner: *'My partner, as we comfort each other' (P69)*. Furthermore, being close to their pets had a unique buffering effect not to feel lonely during self-isolation: *'Except for my puppies and my cat, nothing and nobody' (P108)*. Participants also reported self-help/mutual support from other patients as a key strategy to receive and provide helpful virtual/actual support: *'It helps me following other patients' stories, as they are sick like me. Then I take heart' (P91)*. Lastly, patients showed a deep sense of hope and spirituality, which through *'prayer' (P52)* and *'meditation and yoga' (P97)*, became a real help.

**Dealing with isolation.** To deal with isolation, patients adopted several strategies, including the use of technologies, engaging in daily activities, and spending time in open private spaces. To cope with self-isolation, the important for participants was to keep themselves busy by *'reading, calling friends, keeping in touch with the world on TV (P11)'*. The Internet helped them a lot with this as it allowed virtual contact: *'Seeing my children and grandchildren via the Internet' (P34)*. Patients tried to continue their daily activities, such as *'a little workout' (P27)* and *'the smart working, as it keeps my mind busy, and video calls' (P44)*. Open private spaces, such as the garden, also helped participants spend time in self-isolation with more serenity *'Living in an isolated house with a garden, so that I can be outside to take care of my flowers and prepare the vegetable garden' (P12)*.

## Discussion

This study highlights how patients with cancer perceived self-isolation at home during the Italian mass-quarantine for COVID-19. Their perception was assessed through the ISOLA scale, which was previously developed for cancer patients in protective isolation (Biagioli et al., 2019a) and resulted valid and reliable in the context of self-isolation at home. In particular, the CFA confirmed the three original dimensions and items loading on them, except for item 12 (Staying in isolation makes me feel safe), which loaded on F1 (isolation-related suffering) rather than on F3 (difficulties in the relationship with oneself). It is possible that, in the context of staying at home during a pandemic, perceived safety in isolation (item 12) becomes a measure of the extent to which people accept self-isolation, as they give to it a protective meaning able to lower their suffering (Biagioli et al., 2017). In addition, the ability to give meaning to isolation during a pandemic might be not only part of the patient's inner resources but also reinforced by stay-at-home campaigns. In fact, participants felt moderately safe at home and rarely left their house for more than 6 weeks. On the one hand, their perceived safety might be merely bounded to their self-isolation status, as a considerable number of participants expressed fear of going to the hospital and loss of control with regards to their cancer disease. On the other hand, their perceived risk for SARS-CoV-2

infection and its complications was lower than expected (Paterson et al., 2020; Vaughan, 2011), as only half of the participants believed to be at higher risk than the general population.

Staying at home may sound easier than being isolated in a hospital room (Biagioli, Piredda, Alvaro, & de Marinis, 2017). This was confirmed for several aspects such as the hardness of being shut inside, lack of space to move around, and boredom. One simple explanation is that their own house was considered larger and more comfortable compared to a hospital room. Moreover, most of the participants were not alone at home and could relate with their family members, without substantially changing their affective behaviour even when precautions were adopted. This may indicate that family relationships and affectivity remained essential despite the risk of SARS-CoV-2, given the tendency of cancer patients to seek emotional support from family (Tay, Hegney, & Ang, 2011).

Nevertheless, our results revealed that prolonged self-isolation can have a psychosocial negative impact on people living with cancer, in line with studies emphasising the dangerous implications of quarantine for mental health (Brooks et al., 2020; Stefana et al., 2020). Participants reported substantial problems in relating with significant others, as quarantine prevented them from being close to non-cohabitant loved ones and increased feelings of detachment, even more than protective isolation (Biagioli et al., 2019a). Compared to the latter situation, they also experienced a greater need for someone close to them to talk with, and they felt more cut off from the world, more imprisoned, and more willing to leave their house (Biagioli et al., 2019a). Patients with cancer who experienced greater social problems in quarantine were those with a lower level of education, in line with previous studies underlining the buffering role of education in fostering social cognitive activities while isolated (Biagioli et al., 2019b). In addition, older age and not living with minor children were factors associated with greater problems in the relationship with others. Older adults were not only at higher risk for fatal SARS-CoV-2 infection (Onder et al., 2020) but also disproportionately affected by social isolation during the lockdown period (Armitage & Nellums, 2020). Although the stress of quarantine can be experienced both at individual and dyadic levels (Spinelli, Lionetti, Pastore, & Fasolo, 2020), the parent-child relationship may have contributed to increasing participants' engagement in social activities, given the closure of schools and the need for parents to deal with online classes for their children.

Qualitative data confirmed that self-isolation at home during the lockdown was particularly challenging for participants, who found it difficult to deal with a lack of freedom and social interactions, in line with studies underlining the unfavourable psychological consequences of social isolation (Brooks et al., 2020; Lippi et al., 2020). In the context of having 'little time left to live' in the cancer trajectory, the importance of maintaining social life gains more relevance, given the need to safeguard social relations, daily life activities, perception of social support, and the network in cancer patients (van Rooij, Brom, Youssef-El Soud, van de Poll-Franse, & Raijmakers, 2019). Engaging in daily activities, open private spaces, and the use of technologies helped participants deal with isolation while the closeness of family members and pets, self-help/mutual support, hope, and spirituality became the main drivers of the patients' quality of life. However, the perception of being imprisoned at home might reflect the urgent need for maintaining social relationships and re-establishing everyday life. This also implies regular treatments and check-ups,

which, if withdrawn, can increase patients' uncertainty, fear for the future, and depression (Biagioli, Belloni, Albanesi, Piredda, & Caruso, 2020; Zheng et al., 2020). In addition, several participants were afraid that their cancer care would become less important because of the COVID-19 emergency and that would negatively impact their prognosis. This seems reasonable in light of their urgent need for scans, blood monitoring, chemotherapy, surgery, and transplants, which, if delayed indefinitely, could mean loss of the window to treat. Health professionals should do their best to ensure continuity of care for these patients (ACV, 2020; Chan et al., 2020) while taking a proactive approach to diminish their challenges in accessing healthcare services (Paterson et al., 2020) in order to avoid that cancer patients pay the price for this pandemic.

## **Limits**

Although this study represents a meaningful sight of the cancer patients' perception of staying at home for COVID-19 in Italy, some limitations could be addressed. Firstly, the small sample size may significantly limit the generalizability of the results, as participants could not be considered representative of the whole cancer population in Italy. A second limitation concerns the use of a snowball sampling technique, resulting in a non-probabilistic sample estimation, self-selection, and oversampling of female compared to male as well as other sample characteristics, such as level of education and type of cancer. Although the variables included in this study are meaningful, other variables not considered here, such as the stage of disease and treatment, could have affected the perception of isolation. Moreover, the ISOLA scale showed robust construct validity in this study, but it had been developed for patients undergoing HSCT in protective isolation, which can be considered quite a different situation from quarantine at home. Finally, another limitation is the cross-sectional data collection, which may have prevented gathering information about changes over time.

## **Conclusion**

This study sheds light on the perceptions of self-isolation at home in people living with cancer during the Italian lockdown. The COVID-19 pandemic had a significant impact on their lives in terms of loneliness, detachment from loved ones, access to healthcare services, and feeling safe in a critical situation. Patients who experienced more social problems were the older ones, with lower education, and living without minor children. Although most of the participants felt safe at home, it seems their perception of risk for SARS-CoV-2 infection was somehow mitigated and they were scared both of going to the hospital and losing control of their cancer disease. Perceived safety in the context of a pandemic may be affected by social dynamics, preventive behaviour, and personal beliefs. However, patients with cancer should be protected not only from SARS-CoV-2 infection but also from severe psycho-social implications of the pandemic and treatment delays.

## Declarations

The study purposes, procedures, and data collection were clearly explained to potential participants in the text accompanying the link to the survey. The first part of the survey informed that participation was voluntary, and completion included consent to using data for scientific purposes. Data were collected and held anonymously according to International Ethical Guidelines and Principles for research (CIOMS, 2016). The study was approved by the scientific committee of the Italian Association of Cancer Nurses (AIIAO).

- This study involved human subjects.

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The author confirmed that all appropriate ethical guidelines for the use of human subjects have been followed, any necessary IRB and/or ethics committee review has been obtained, and information about the IRB/ethics committee is included in the manuscript.

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The author has confirmed that all necessary patient/participant consent or assent has been obtained and the appropriate institutional forms have been archived. If the IRB/ethics committee waived the requirement for patient/participant consent or assent, an explanation for the waiver is included in the text.

- The author has confirmed that a statement listing potential conflicts of interest or lack thereof is included in the text.

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## Tables

**Table 1.** Participants' socio-demographic characteristics (n = 195)

|                           | n    | %      |
|---------------------------|------|--------|
| Sex                       |      |        |
| Male                      | 47   | 24.1   |
| Female                    | 148  | 75.9   |
| Age (mean, SD)            | 50.3 | (11.2) |
| Age                       |      |        |
| < 40 years                | 32   | 16.5   |
| 40-50 years               | 68   | 35.1   |
| 51-60 years               | 52   | 26.8   |
| > 60 years                | 42   | 21.6   |
| Education                 |      |        |
| ≤ Secondary school        | 29   | 14.9   |
| High school               | 99   | 51.0   |
| University                | 45   | 23.2   |
| Postgraduate              | 21   | 10.8   |
| Marital status            |      |        |
| Single                    | 29   | 14.9   |
| Partnered                 | 129  | 66.5   |
| Divorced/ Widowed         | 36   | 18.6   |
| Italian region            |      |        |
| North                     | 75   | 38.9   |
| Centre                    | 51   | 26.4   |
| South                     | 67   | 34.7   |
| Cancer diagnosis          |      |        |
| Haematology               | 100  | 51.3   |
| Breast cancer             | 51   | 26.2   |
| Others                    | 44   | 22.6   |
| Religiosity               |      |        |
| Believer                  | 90   | 47.1   |
| Quite a believer          | 48   | 25.1   |
| Not believer/indifferent  | 53   | 27.7   |
| Living with               |      |        |
| Partner                   | 48   | 25.0   |
| Partner and children      | 74   | 38.5   |
| Alone                     | 17   | 8.9    |
| Other                     | 53   | 27.6   |
| Living with children <18y |      |        |
| Yes                       | 75   | 39.1   |
| No                        | 117  | 60.9   |

**Table 2.** Participants' opinion, behaviour, and experiences during self-isolation (n = 195)

|  | n   | %    |
|--|-----|------|
| Time in self-isolation   |     |      |
| < 4 weeks  | 57  | 29.2 |
| 4-6 week   | 61  | 31.3 |
| > 6 weeks  | 77  | 39.5 |
| I leave my house   |     |      |
| Every day  | 15  | 7.7  |
| Sometimes (2-3 times per week)   | 23  | 11.9 |
| Rarely   | 115 | 59.3 |
| Never  | 41  | 21.1 |
| Changes in the relationship with family members <sup>†</sup>                 |     |      |
| No kisses and hugs   | 61  | 31.9 |
| Social distance  | 23  | 12.0 |
| Separate rooms   | 13  | 6.8  |
| Nothing changed  | 107 | 56.0 |
| Other  | 13  | 6.8  |
| SARS-CoV-2 infection   |     |      |
| I believe I am at higher risk  | 105 | 53.8 |
| I believe I am not at higher risk  | 90  | 46.2 |
| I will suffer from severe consequences in case of infection due to my cancer |     |      |
| Very much/Completely   |     |      |
| Quite a bit  | 99  | 50.8 |
| A little/Not at all  | 46  | 23.6 |
|  | 50  | 25.6 |
| My cancer will become less important   |     |      |
| Very much/Completely   | 47  | 24.5 |
| Quite a bit  | 38  | 19.8 |
| A little/Not at all  | 107 | 55.7 |
| Health status under control  |     |      |
| No   | 56  | 29.0 |
| Yes  | 137 | 71.0 |
| Fear of going to the hospital  |     |      |
| Not at all   | 16  | 8.3  |
| A little   | 65  | 33.7 |
| Quite a bit  | 40  | 20.7 |
| Very much/Completely   | 72  | 37.3 |

<sup>†</sup> multi response variable

**Table 3.** Mean scores of the 14 items about perceived isolation related to COVID-19 (n = 195)

| Item   | Mean | SD   | Skew  | Kurt  |
|--|------|------|-------|-------|
| 1. I get bored because time passes slowly.                               | 2.06 | 1.00 | 1.07  | 1.04  |
| 1. I miss the contact with the outside world.                            | 3.18 | 1.14 | 0.06  | -0.91 |
| 1. I can stay in the isolation room with serenity.                       | 2.79 | 0.92 | -0.10 | 0.07  |
| 1. Being shut inside my home is hard.                                    | 2.66 | 1.09 | 0.44  | -0.46 |
| 1. It is a problem for me not being able to stay close to my loved ones. | 3.35 | 1.17 | -0.09 | -0.97 |
| 1. I lack space to move around.  | 2.23 | 1.28 | 0.86  | -0.33 |
| 1. Staying in isolation helps me to look at life from a new perspective. | 2.80 | 1.23 | 0.09  | -1.00 |
| 1. I need someone close to me to talk with.                              | 2.53 | 1.22 | 0.65  | -0.44 |
| 1. I feel cut off from the world.  | 2.28 | 1.31 | 0.92  | -0.24 |
| 10. Staying here on my own allows me to think more about myself.         | 2.91 | 1.19 | 0.13  | -0.83 |
| 11. I feel imprisoned.   | 2.30 | 1.30 | 0.79  | -0.46 |
| 12. Staying in isolation makes me feel safe.                             | 2.90 | 1.24 | 0.04  | -0.92 |
| 13. I feel detached from my loved ones.                                  | 3.27 | 1.27 | -0.07 | -1.13 |
| 14. I feel I want to leave my house.                                     | 2.87 | 1.21 | 0.40  | -0.87 |

*Note: SD = standard deviation; Skew = skewness; Kurt = kurtosis*

**Table 4.** Categories, sub-categories and quotes of qualitative data from the two open-ended questions

| Question  | Main Category                                   | Sub-category                                     | Quotes  |                        |   |
|---|---|--|---|------------------------|---|
| What is the worst aspect of this isolating condition for you? | <i>Lack of freedom and social life</i>          | The deprivation of freedom and mobility          | I miss the freedom to move around (P86);<br>Feeling in prison (P141);<br>The lack of freedom (P155);  |                        |   |
|   |   | Detachment from family members                   | I miss the rest of my family (P13);<br>I miss the physical contact, especially with my son. His hugs are my strength, my oxygen (P16);<br>Not being allowed to meet my parents, siblings, nephews and friends (P176); |                        |   |
|   |   | Lack of social interactions                      | Not being allowed to hug anyone and give them my smiles and take energy from their looks (P1);<br>Not having interpersonal relationships (P60);<br>Not having a social life anymore (P104);                           |                        |   |
|   |   | Missing 'everyday life'                          | I miss my job (P69);<br>I miss my usual life, already partially compromised by the disease last year (P116);<br>Having suddenly interrupted my life (P183);   |                        |   |
|   | <i>Uncertainty and worries</i>                  | Unknown future                                   | How and when it will end (P34);<br>The feeling of being in an endless tunnel and having very few alternatives available (P50);<br>Uncertainty (P167);   |                        |   |
|   |   | The fear of infection for oneself and loved ones | The fear of infection because of my health condition (P39);<br>Fear of getting COVID-19 and infect my children (P109);<br>Fear of contagion (P159);   |                        |   |
|   |   | Economic difficulties                            | The economic aspect (P45);<br>The perplexity about the economic solution of the problem (P54);<br>The job uncertainty (P189);   |                        |   |
|   |   | Concerns on the health system                    | Anxiety about not being able to go to the hospital (P18);<br>Not having treatment and check-ups (P47);<br>Understanding that we can't trust anyone, from those who govern us to doctors (P70);                        |                        |   |
|   |   | What is helping you in this isolating situation? | <i>Feeling supported</i>  | Closeness of family    | My children (P17);<br>My little girl and my husband (P19);<br>My partner, as we comfort each other (P69);   |
|   |   |  |   | Being close to my pets | Having a cat (P12);<br>Except for my puppies and my cat, nothing and nobody (P108);<br>The fact of not being alone, because I have my husband, two teenage children and a dog (P142); |
| Self-help/mutual  | Talking to other patients and trying to comfort |  |   |                        |   |

|                               |                              |   |
|-------------------------------|------------------------------|---|
|                               | support                      | them. I get so many requests for help; I am moved to be told 'thank you' (P1);<br>It helps me following other patients' stories, as they are sick like me. Then I take heart (P91);   |
|                               | Hope and spirituality        | Prayer (P52);<br>Meditation and yoga (P97);<br>Faith and hope (P130);   |
| <i>Dealing with isolation</i> | Use of technologies          | Reading, calling friends, keeping in touch with the world on TV (P11);<br>After so many days, the only thing that helps me is to exercise and YouTube videos help with this (P90);<br>Seeing my children and grandchildren via the Internet (P34);  |
|                               | Engaging in daily activities | A little workout (P27);<br>The smart working, as it keeps my mind busy, and video calls (P44);<br>Books, music and TV series (P92);   |
|                               | Open private spaces          | Living in an isolated house with a garden, so that I can be outside to take care of my flowers and prepare the vegetable garden (P12);<br>It helps me a lot to have a house with a garden (P41);<br>Going out into the home garden and thereby having the possibility not to be staring at four walls all day (P134); |

## Figures

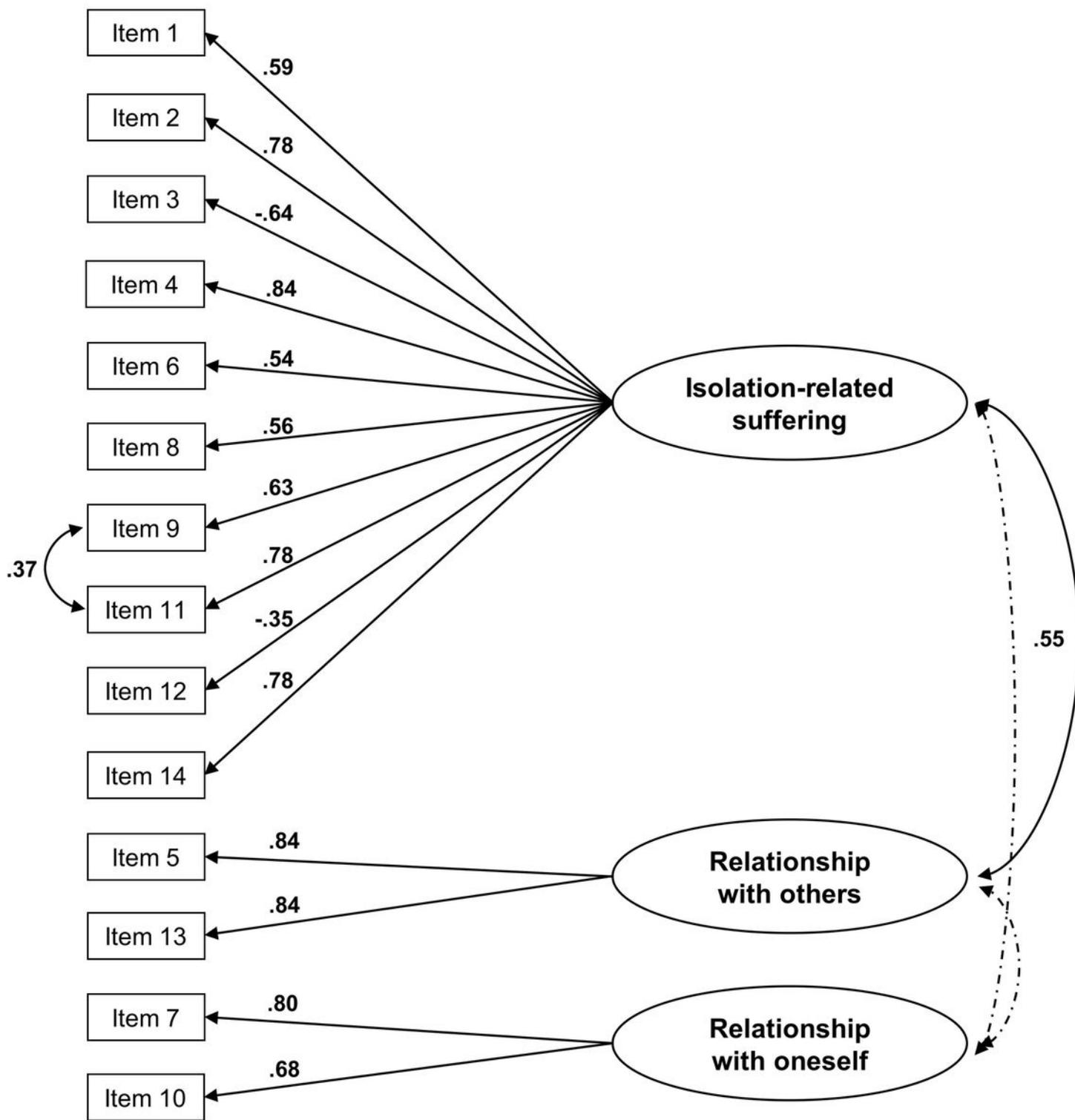


Figure 1

Figure 1. CFA model of the ISOLA scale (n = 195)