

Life and Love Stories During Corona Times: Cancer Patients and The General Public

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1. Abstract

1.1. Introduction: The past COVID pandemic clearly showed us how difficult relationships (either as oncology patients, or as a healthy human being/a couple) can be. Being socially isolated or precisely the opposite, e.g., living tightly together can become difficult during extreme situations. This paper focuses on the quality of relationships during the COVID pandemic and beyond; differences between the Spanish and Dutch population are compared.

1.2. Methods: With short, on-line questionnaires focusing on present as well as past COVID-experiences among the Dutch (n=70) and Spanish (n=98) general public, we tried to get a grip on the emotional impact of a serious crisis, such as the COVID pandemic.

1.3. Results: Our Spanish sample almost all reported that well-being changed during the pandemic (95%). Only a few (9%) of our Spanish respondents reported to experience problems of loneliness during the COVID-pandemic; this percentage was much higher among the Dutch sample (39% of all participants). Emotional support was generally reported as rather high among Spanish people ranging from 95% or higher to the importance they attached of having a special person being around as well as family support. The added value Dutch persons attached towards family support was a little lower (70% and 65% respectively). The frequency of

people not being anxious was higher among the Dutch sample (43% versus 15% in the Spanish sample). Spanish people however at the same time experienced (despite their reported anxiety) a more meaningful life (87% of people versus 13% of people in the Dutch sample).

1.4. Discussion: Although high frequencies of emotional support were reported among Dutch and Spanish people, relationships in itself either seemed to have become more difficult or stronger. It further seemed that participants' mood did not have a tremendous impact on the perceived quality of their relationships. Regardless in how difficult a situation can be, your own mindset as well as cultural differences to a great extent seems to determine perceived well-being.

2. Introduction

The past COVID situation clearly showed us how difficult relationships (either as oncology patients, or as a healthy human being/a couple) can be [1, 2]. Being socially isolated or precisely the opposite, e.g., living tightly together can become difficult in extreme situations. At the beginning of the COVID-period, Esther Perel described this as follows: 'I think, in general, when people live in acute stress, either the cracks in their relationship will be amplified or the light that shines through the cracks will be ampli-

fied. You get an amplification of the best and of the worst.' This not only holds for a pandemic such as COVID, but for every situation where either on a national or on a more individual level crises take place (take for instance the present war in Ukraine, with disruptions of health services to an even greater extent) [3-5].

Traditionally, positive emotions and thoughts, strengths, and the satisfaction of basic psychological needs for belonging, competence and autonomy have been seen as the cornerstones of psychological health [6, 7]. In our previous papers and blogposts [2 8 9], we already argued that the experiences we gained during the COVID pandemic, could be regarded as a starting point of being aware about the importance of some crucial elements of well-being, e.g., the importance of connection and the quality of relationships. In this context, we also referred to compassion, since compassion is often referred as using and transferring your empathic skills by helping and promoting someone's well-being [10, 11].

Being aware of the importance of compassion and the added value of high-quality relationships, social isolation as experienced during the COVID pandemic might reflect an opposite trend. Because social isolation happens steadily, e.g., it not happens from one single moment to another moment; it requires consciousness to be aware of everyone's behavioral changes during social isolation. It probably happens among everyone.

Taking the Dutch COVID-pandemic as an example, the number of optimistic messages in the media (such as newspapers) were rather high during the beginning of this pandemic, but the tone of voice as well as the frequency of optimistic messages changed when months and subsequently years passed by. In other words: Whereas our 'battery' was sufficiently loaded to be able to deal with the obstacles and isolation during the beginning of this crisis, this became far more difficult when this situation endured.

This paper focuses on the quality of social relationships during the COVID pandemic and beyond; differences between the Spanish and Dutch population are compared.

3. Methods

3.1. Recruitment

In total, 98 (healthy) participants in Spain and 70 (healthy) participants in the Netherlands filled out a short online questionnaire about relationship experiences and social support (Spring 2022), focusing on the present situation as well as the past COVID pandemic. In both countries, people were approached by a researcher (LLG and HMB). Moreover, a snowballing technique was used to recruit an as much diverse reflection of the general population. We so tried to gather a broad sample that varied across age and gender. The average age of the Dutch population was ~ 35 years; the average population of the Spanish population was a little higher with ~45 years.

3.2. Questionnaire

The questionnaire combined different sets of questions regarding topics such as well-being, the quality of relationships, social sup-

port and experiences about the COVID pandemic. The questionnaire consisted of a combination of the Multidimensional Scale of Perceived Social Support (MSPSS) [12], the Relationship Satisfaction Scale (RSAT) [13], the Short Warwick-Edinburgh Well-being [14] and the ONS subjective well-being questions [15] The English version was translated towards a Spanish and Dutch version. In this exploratory pilot study, we did not gather additional information as to whether our participants were having a romantic relationship, and whether they were having children.

3.3. Data analysis

Quantitative data were analyzed with SPSS. We illustrate our quantitative results with experiences from Spanish and Dutch oncology patients who spoke with us about their experiences during the COVID pandemic (the beginning of 2021). A questionnaire study among a healthy population did not require medical ethical review. The quotes represent an illustration of the oncology population and can be regarded as a secondary analysis of data, which are currently under review in another paper (BMJ Open).

4. Results

Our Spanish sample almost all reported that well-being changed during this specific COVID-period (95%) (Table 1), whereas only half of them reported that their mood had changed because of the presence of the COVID pandemic. This finding contrasted with what we found among the Dutch sample, in which well-being changed in 47% of participants, and in which their mood remained relatively stable (61% of Dutch participants). Dutch participants however at the same time acknowledged that their relationships had become more difficult during the pandemic (62%) whereas only 20% of Spanish participants experienced difficulties during the pandemic.

Only a few (9%) of our Spanish respondents reported to experience problems of loneliness during the COVID-pandemic; this percentage was much higher among the Dutch sample (39% of Dutch participants).

Emotional support (Table 2) was generally reported as rather high among Spanish people ranging from 95% or higher to the importance they attached of having a special person being around as well as family support. In general, all percentages were a little lower among the Dutch sample, which could imply a more individualistic life style. Although all frequencies that depicted high forms of emotional support, little lower frequencies were reported as to whether people experienced real help from friends (89% Spain versus 79% Netherlands), and the ability to really talk with friends (91% Spain versus 65% Netherlands).

Our Spanish and Dutch sample both appeared to be satisfied with their life while filling out questions about the past COVID pandemic: 88% of our Spanish sample was extremely positive as compared to 82% of our Dutch sample. However, the frequency of people being anxious was higher among the Dutch (43% of participants) compared to the Spanish sample (15% of participants).

Spanish people reported to experience a more meaningful life (87%) compared to our Dutch participants (13%).

Table 1: Experiences during the COVID-19 pandemic.

		Spain	The Netherlands
		N=98	N=70
		%	%
<i>My well-being changed during the pandemic</i>	Yes	95	47
	No/neutral	2	33
<i>My mood changed during the pandemic</i>	Yes	56	39
	No/neutral	44	61
<i>My relationships have become more difficult during the pandemic¹</i>	Not at all	20	62
	Neutral	20	21
	Yes, extremely	60	17
<i>My relationships have become stronger during the pandemic¹</i>	Not at all	23	31
	Neutral	35	34
	Yes, extremely	42	34
<i>I experience periods of loneliness¹</i>	Not at all	73	43
	Neutral	18	18
	Yes, extremely	9	39

1. Not at all (score 1-2), Neutral (Score 3), Yes, extremely (Score 4-5).

“Well, look, it affected me. Sure, it affected me [COVID pandemic]. [...] How it has given me to be in those moments that have been the worst at the beginning and then all the following months.” **Patient 8 (Spanish breast cancer patient)** “I had been reading the news too much and I started thinking fuck, you’ll see, you will have survived cancer and then you will die from a thing like corona”. **Patient 8 (Dutch breast cancer patient)**.

Table 2: Emotional support.

Relational questions		Spain	Netherlands
		N=98	N=70
		%	%
There is a special person around when I am in need	No I disagree	2	13
	Neutral	3	19
	I completely agree	95	68
There is a special person with whom I can share my joys and sorrows	No I disagree	2	13
	Neutral	2	17
	I completely agree	96	70
My family really tries to help me	No I disagree	2	12
	Neutral	1	17
	I completely agree	97	71
I get the emotional help and support I need from my family	No I disagree	3	15
	Neutral	6	19
	I completely agree	91	66
I have a special person who is a real source of comfort to me	No I disagree	3	12
	Neutral	2	17
	I completely agree	95	71
My friends really try to help me	No I disagree	4	6
	Neutral	7	16
	I completely agree	89	78
I can count on my friends when things go wrong	No I disagree	4	3
	Neutral	2	10
	I completely agree	94	87
I can talk about my problems with my family	No I disagree	7	15
	Neutral	2	20
	I completely agree	91	65
I have friends with whom I can share my joys and sorrows	No I disagree	5	1
	Neutral	1	4
	I completely agree	94	95
There is a special person in my life who cares about my feelings	No I disagree	3	20
	Neutral	1	22
	I completely agree	96	66
My family is willing to help me make decisions	No I disagree	2	12
	Neutral	1	19
	I completely agree	97	69
I can talk about my problems with my friends	No I disagree	5	3
	Neutral	4	6
	I completely agree	91	91

1 No, I disagree (Score 1-3); Neutral (Score 7): Yes, I completely agree (Score 5-7).

“It is very important to have people around you. [...] I am a sick person, but I do not consider myself dependent. It is important though (to have people around you).” **Patient 6 (Spanish breast cancer patient)**.

“I miss the house [walk-in house for cancer patients] very much. Two times in the week I would go there to work out and I had my sporting buddies. That’s really something you miss because... you know, you can’t go whining to your friends about cancer every time. And in the house you find so much recognition in 1 word... yeah because everyone is going through the same thing... yeah, you can share your worries and you are being seen and being heard and... yeah that’s something you miss.” **Patient 1 (Dutch breast cancer patient)**.

Table 3: Present well-being.

Relational questions		Spain	Netherlands
		N=98 %	N=70 %
How satisfied are you with your life, in general, today?	Not at all	5	6
	Neutral	7	12
	Extremely positive	88	82
How happy were you in general, yesterday?	Not at all	11	6
	Neutral	21	12
	Extremely positive	68	82
How anxious have you been in general, yesterday?	Not at all	37	25
	Neutral	48	32
	Extremely positive	15	43
How meaningful have you felt in general, yesterday?	Not at all	4	50
	Neutral	9	37
	Extremely positive	87	13

1; Not at all (Score 1-4); Neutral (Score 5); 10; Extremely positive (Score 6-10)

5. Discussion

In this short report, based on a short online survey, we depict general public's emotional state and well-being during the COVID pandemic. By taking the last COVID-wave in Spain and the Netherlands as our starting point, some remarkable findings, that warrant further reflection, are brought forward. According to our participants, although high frequencies of emotional support were reported in both samples, relationships in itself either seemed to have become more difficult or stronger. It further seemed as if participants' mood did not have a tremendous impact on the perceived quality of their relationships. The Spanish participants however reported to experience a more meaningful life as compared to the Dutch participants.

Before discussing these findings, some limitations need to be taken into account. The quantitative findings reflect one single moment and we did not assess participants' state of mind while filling out the questionnaire; it may well be possible that a questionnaire follow-up after one month would have resulted in different findings [16]. Furthermore, although we approached healthy persons across age-categories, and the number of men and women were considered equal, privacy reasons led us to not collect identifiable data in both samples except gender and age, which showed equal distribution among both groups. Finally, this is an exploratory study and the number of participants in each country are limited.

We observed high levels of emotional support and life satisfaction in both samples; this to a great extent seems equivalent with findings from previous studies in which patients'/'ordinary' people report similar ratings of quality of life in difficult situations [17]. Other studies in which the COVID pandemic was observed to a certain extent report similar findings, such as the experiences of loneliness [18]. It suggests that regardless in how difficult a situation can be, your own mindset to a great extent determines perceived well-being. These findings are also in line with our paper that focuses on the role of optimism in patients with incurable cancer [8]. Intimate relationship questions have been shown to be difficult to broach quantitatively, and in our interviews we

also only shortly touched upon intimacy. This seems an interesting finding in itself. Intimacy-related questions, are – by their very nature - rather personal and this possibly not differs during or outside a pandemic, like COVID.

Rene ten Bos describes this as follows [19, 20]: 'In summary, we can state that when it comes to intensities, words suddenly appear to have weight disturbances. They are too heavy, they are too light, it is never right.' It seems as if this also happened in our study; only interviews appeared to be sufficient to get some insight about intimacy related questions. Perhaps, if words are too heavy, a more appropriate way of communication could be via music or poetry. In fact, this is also what happened during the pandemic:

In Italy, people sang on balconies, facilitating feelings of belongingness in their neighbourhood [21]. Music and poetry have been shown to be of great help in difficult situations like crises; When we start listening to certain songs, a feeling of love often automatically pops up. The added value of music has already been proven in for instance the finishing of chemotherapy courses [22], as well as other interventions that could improve patients' quality of life. [23] It is this human connection, presence and 'being there'. Although life stories are not the same as love stories, since the latter can to a certain extent be disconnected from other realities, it at least shows that to be able to encapsulate life and love stories, the role and value of emotions need to be included also. High-impact journals such as the NEJM, JCO and JAMA Oncology now all have specific sections in which such personal reflections remain the primary focus, such as the section 'Poetry' [24-27].

While providing insight in how patients or healthy people may experience their relationships during difficult time-periods, such as a COVID pandemic, new and deeper forms of communication seem to have been re-invented that cannot always be captured in questionnaires/interviews but in which music, poetry and a higher state of consciousness probably starts to play a bigger role. Since we are currently exploring new ways to improve healthcare in a post pandemic period also, new forms of communication (like poetry and music) deserve far more attention.

References

1. Buiting HM. The impact of relationships on quality of life during Corona times. In: EAPC. 2021.
2. Buiting H. Well-Being and Being Apart: Relationship Challenges During COVID-19. 2021.
3. War in Ukraine Disrupts Trials, Cancer Care. *Cancer Discov.* 2022.
4. Fontanarosa PB, Flanagan A, Golub RM. Catastrophic Health Consequences of the War in Ukraine. *Jama* 2022.
5. Rubin R. Clinical Trials Disrupted During War in Ukraine. *JAMA.* 2022.
6. Kashdan TB, Rottenberg J. Psychological flexibility as a fundamental aspect of health. *Clinical psychology review.* 2010; 30(7): 865-78.
7. Buiting H, Ravensbergen L, van Schaik C, et al. Small stuff, deep underlying emotions: A laugh, a smile and a sigh. *Journal of Anesthesiology and Pain Therapy.* 2022; 3(1): 5-7.
8. Gonzalez L, Lara Álvarez MÁ, Beernaert K. The role of optimism on patients' well-being living longer with incurable breast cancer: A qualitative study in Spain *BMJ Open* Provisionally accepted.
9. Buiting HM, CC van Alphen E. Living with COVID: What we learned from patients with incurable cancer during challenging times: *Medical Humanities.* 2022.
10. Ricard M. *Altruisme: de kracht van compassie: ten Have.* 2013.
11. Perez-Bret E, Altisent R, Rocafort J. Definition of compassion in healthcare: a systematic literature review. *Int J Palliat Nurs.* 2016; 22(12): 599-606.
12. Zimet GD, Powell SS, Farley GK. Psychometric characteristics of the Multidimensional Scale of Perceived Social Support. *J Pers Assess.* 1990; 55(3-4): 610-7.
13. Raffagnino R, Matera C. Assessing relationship satisfaction: Development and validation of the dyadic-familial relationship satisfaction scale. *Journal of Couple & Relationship Therapy.* 2015;14(4): 322-41.
14. Tennant R, Hiller L, Fishwick R. The Warwick-Edinburgh Mental Well-being Scale (WEMWBS): development and UK validation. *Health and Quality of Life Outcomes.* 2007; 5(1): 63.
15. Zimet GD, Dahlem NW, Zimet SG. The multidimensional scale of perceived social support. *Journal of personality assessment.* 1988; 52(1): 30-41.
16. McClimans L, Bickenbach J, Westerman M. Philosophical perspectives on response shift. *Qual Life Res.* 2013; 22(7): 1871-8.
17. Frankl V. *Man's search for meaning: The classic tribute to hope from the holocaust.* London: Random House Group Limited. 1946.
18. Garutti M, Cortiula F, Puglisi F. Seven Shades of Black Thoughts: COVID-19 and Its Psychological Consequences on Cancer Patients. *Front Oncol.* 2020; 10: 1357.
19. Ten Bos R. *Stilte, geste, stem.* Amsterdam: Boom. 2011.
20. Ten Bos R. *Een woord heeft geen geur. Stilte, geste, stem.* Amsterdam: Boom. 2011.
21. Corvo E, De Caro W. COVID-19 and spontaneous singing to decrease loneliness, improve cohesion, and mental well-being: An Italian experience. *Psychol Trauma.* 2020; 12(S1): S247-s48.
22. Pils S, Ott J, Reinhaller A. Effect of Viewing Disney Movies During Chemotherapy on Self-Reported Quality of Life Among Patients With Gynecologic Cancer: A Randomized Clinical Trial. *JAMA Network Open.* 2020; 3(5): e204568-e68.
23. McCrary JM, Altenmüller E, Kretschmer C. Association of Music Interventions With Health-Related Quality of Life: A Systematic Review and Meta-analysis. *JAMA Network Open.* 2022; 5(3): e223236-e36.
24. Geynisman DM. Doctor, Where Art Thou? *Journal of Clinical Oncology.* 2013; 31(12): 1606-08.
25. Steensma DP. Art of Oncology: New Voices Wanted. *Journal of Clinical Oncology.* 2011; 29(25): 3343-44.
26. Xiang DH. How to Breathe. *JAMA Oncology.* 2022.
27. Rabinowitz Steele NZ. The Patient Resident. *New England Journal of Medicine.* 2022; 386(11): 1010-11.