

ORIGINAL ARTICLE

Evaluating the impact of COVID-19 on supportive care needs, psychological distress and quality of life in UK cancer survivors and their support network

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Abstract

Objectives: The COVID-19 pandemic is having considerable impact on cancer care, including restricted access to hospital-based care, treatment and psychosocial support. We investigated the impact on unmet needs and psychosocial well-being.

Methods: One hundred and forty four participants (77% female), including people with cancer and their support networks, were recruited. The most prevalent diagnosis was breast cancer. Forty-one participants recruited pre-pandemic were compared with 103 participants recruited during the COVID-19 pandemic. We measured participants' unmet supportive care needs, psychological distress and quality of life.

Results: Half of our patient respondents reported unexpected changes to treatment following pandemic onset, with widespread confusion about their longer-term consequences. Although overall need levels have not increased, specific needs have changed in prominence. People with cancer reported significantly reduced anxiety ($p = 0.049$) and improved quality of life ($p = 0.032$) following pandemic onset, but support network participants reported reduced quality of life ($p = 0.009$), and non-significantly elevated anxiety, stress and depression.

Conclusion: Psychological well-being of people with cancer has not been detrimentally affected by pandemic onset. Reliance on home-based support to compensate for the lost availability of structured healthcare pathways may, however, explain significant and detrimental effects on the well-being and quality of life of people in their support and informal care networks.

KEYWORDS

cancer, COVID-19, distress, oncology, psychosocial, quality of life, SARS-Cov-2, unmet needs

1 | INTRODUCTION

The COVID-19 pandemic has radically changed the management of cancer patients (Archer et al., 2020; Tsamakidis et al., 2020), a population with intrinsically higher lethality from SARS-Cov-2 infection

(Pinato et al., 2020). Social distancing, quarantine and lockdown measures have limited access not only to clinical care (Neal et al., 2020) but also to supportive and psychosocial care (Archer et al., 2020). The social repercussions of such measures are unlikely to be short-lived (Young et al., 2020) and include a vast range of additional

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stressors (e.g. caring responsibilities and financial pressures) for both patients and their informal support networks (Nekhlyudov et al., 2020). Although clinical and psychosocial support are available via telehealth (Archer et al., 2020) and remote consultation, these technologies may not meet all patient needs effectively and require further evidence about their accessibility, acceptability and influence on patient outcomes (Neal et al., 2020).

Psychosocially, COVID-19 is thought to contribute to uncertainty, isolation and loneliness in cancer patients (Nekhlyudov et al., 2020; Tsamakis et al., 2020), and treatment delays correlate with exacerbated fear of progression, anxiety and depression (Chen et al., 2020). However, there is no systematic evidence to demonstrate this using patient-reported outcome data. In this UK-wide study, we hypothesised that the pandemic resulted in changed unmet needs, increased distress and poorer quality of life (QoL), in people affected by cancer.

2 | METHODS

2.1 | Participants and procedures

This prospectively planned, cross-sectional study compared two samples of participants, recruited at two time points: June/July 2019 (pre-pandemic, $n = 41$) and June/July 2020 (during pandemic, $n = 103$). Eligible participants were people aged >16 years seeking cancer-related support (for their own diagnosis, or that of someone in their support networks) from UK-based Maggie's Cancer Centres.

Ethical approval was first granted by the University of Chester Department of Psychology Ethics Committee in May 2019. The original aim of this prospective study was to track the unmet needs of cancer survivors engaging with charity-based cancer support services, and how these related to psychosocial well-being. A subsequent ethics amendment granted in April 2020 allowed us to add additional questions pertaining to COVID-19 and to build in a secondary research question to reflect the impact of the onset of the COVID-19 pandemic, as is reported in this paper.

The 2019 sample was recruited by an on-site researcher. Following consent, participants completed paper-and-pen questionnaires. Because of social distancing, the 2020 sample was recruited through the Maggie's Online Centre and organisational-based social media adverts, with participants directed to a questionnaire hosted on JISC Online Surveys. Recruiting via social media has been demonstrated an effective way of recruiting cancer survivors; however, the nature of social media means that it is impossible to provide an accurate response rate as the baseline population rate is highly variable over time (Hulbert-Williams et al., 2019).

2.2 | Measures

Participants self-reported demographic and clinical information. As primary study endpoints, we selected validated self-report

questionnaires of psychosocial well-being. Patient unmet needs were assessed using the short form of the Supportive Care Needs Survey (SCNS-SF34; Boyes et al., 2009), a 34-item measure assessing unmet needs across five domains of care: health system and information; psychological; physical and daily living; patient care and support; and sexuality needs. The SCNS-SF34 has been validated in two separate samples of adult cancer patients ($N = 888$ and $N = 250$, respectively), representing a range of cancer sites (Boyes et al., 2009). Support network unmet needs were assessed using the closely related Supportive Care Needs Survey—Partners and Caregivers (SCNS-P&C; Girgis et al., 2011), a 44-item measure of four domains of unmet needs: healthcare service needs; psychological and emotional needs; work and social needs; and information needs. The SCNS-P&C has previously been validated in a sample of 547 caregivers of patients living with colorectal, breast, prostate, lung, or head and neck cancer, leukaemia, non-Hodgkin's lymphoma or melanoma (Girgis et al., 2011). Higher scores on both versions of the SCNS indicate greater unmet needs (Boyes et al., 2009; Girgis et al., 2011).

Patients' QoL was assessed using the Functional Assessment of Cancer Therapy—General (FACT-G; Cella et al., 1993), a 33-item assessment of physical, social/family, emotional and functional cancer-related well-being over the previous seven-day period. The FACT-G has previously been validated in a sample of 545 patients with a range of cancer diagnoses (Cella et al., 1993). We used the Caregiver Oncology Quality of Life questionnaire (CarGOQoL; Minaya et al., 2012) to assess QoL in support network participants. This 29-item measure indicates ten 10 dimensions of QoL including psychological well-being; burden; relationship with health care; administration and finance; coping; physical well-being; self-esteem; leisure time; social support; and private life. The CarGOQoL has previously been validated in a sample of 837 caregivers of cancer patients. Higher scores on both the FACT-G and CarGOQoL indicate greater QoL. Depression, anxiety and stress were assessed in both participants groups using the 21-item Depression, Anxiety and Stress Scales (DASS; Lovibond & Lovibond, 1995) (all participants) to assess anxiety, depression and stress. The 21-item DASS has previously been validated in a sample of 376 patients with cancer of various sites (Fox et al., 2018). Higher scores on the DASS indicate more severe depression, anxiety and stress, respectively.

The patient sample recruit in 2020 only answered additional questions about the perceived impact of COVID-19 on cancer care and treatment.

2.3 | Statistical analysis

Variables were calculated following standard test scoring guidelines. Missing data were not imputed. We report difference in mean unmet need scores at domain level, and change in mean ranking of individual needs items. We used ANOVA with Cohen's d effect size estimates and Reliable Change Indices (RCIs) to explore differences in distress and QoL.

TABLE 1 Baseline socio-demographic and clinical profile of the sample

	Cancer patients			Support Network				
	2019 (n = 29)	2020 (n = 92)	p	2019 (n = 12)	2020 (n = 11)	p		
Gender								
Male	2 (6.9%)	21 (22.8%)	0.071	6 (50.0%)	1 (9.1%)	0.069		
Female	25 (86.2%)	70 (76.1%)		6 (50.0%)	10 (90.0%)			
Missing	2 (3.9%)	1 (1.1%)						
Age (years)								
Mean	57.63	65.26	0.503	60.04	45.67	0.010		
S.D.	11.88	9.37		10.88	14.76			
Country								
England	23 (79.3%)	40 (43.5%)	0.018	8 (66.7%)	6 (54.5%)	0.485		
Scotland	6 (20.7%)	33 (35.9%)		4 (33.3%)	3 (27.3%)			
Wales		6 (6.5%)			2 (18.2%)			
Missing		13 (14.1%)						
Cancer Type								
Brain/CNS	1 (3.4%)	4 (4.3%)	0.074	2 (16.7%)	1 (9.1%)	0.909		
Breast	17 (58.6%)	38 (41.3%)		1 (8.3%)	2 (18.2%)			
Gynaecological	3 (10.3%)	3 (3.3%)		1 (8.3%)				
Haematological	1 (3.4%)	9 (9.8%)		1 (8.3%)	2 (18.2%)			
Head & Neck	1 (3.4%)	3 (3.3%)						
Lower GI / Bowel	1 (3.4%)	6 (6.5%)		1 (8.3%)	1 (9.1%)			
Lung		4 (4.3%)						
Pancreatic	1 (3.4%)			1 (8.3%)				
Prostate	2 (6.9%)	11 (12.0%)		2 (16.7%)	1 (9.1%)			
Sarcoma		2 (2.2%)			2 (18.2%)			
Upper GI		2 (2.2%)			1 (9.1%)			
Urology / Bladder		2 (2.2%)		2 (16.7%)				
Unknown Primary					1 (9.1%)			
Other	2 (6.9%)	7 (7.6%)		1 (8.3%)				
Missing		1 (1.1)						
Time since diagnosis								
<2 months	18 (62.1%)	1 (1.1%)		<0.001	8 (66.7%)		1 (9.1%)	0.046
2-12 months	3 (10.3%)	18 (19.6%)	1 (8.3%)		3 (27.3%)			
13-24 months	4 (13.85)	19 (20.7%)	1 (8.3%)		1 (9.1%)			
2-5 years	3 (10.3%)	35 (38.0%)	2 (16.7%)		6 (54.5%)			
<5 years		18 (19.6%)						
Missing	1 (3.4%)	1 (1.1%)						
Treatment Phase								
Active Treatment	15 (51.7%)	25 (27.2%)	0.027	7 (58.3%)	4 (36.4%)	0.491		
Completed	8 (27.6%)	23 (25%)		1 (8.3%)	1 (9.1%)			
Continuing hormone therapy	6 (20.7%)	21 (22.8%)		2 (16.7%)	1 (9.1%)			
Watch and wait / Active Surveillance		12 (13.0%)			2 (18.2%)			
Other				1 (8.3%)	3 (27.3%)			
Missing		1 (1.1%)		1 (8.3%)				

(Continues)

TABLE 1 (Continued)

	Cancer patients			Support Network		
	2019 (n = 29)	2020 (n = 92)	p	2019 (n = 12)	2020 (n = 11)	p
Use of Maggie's Centres						
New Visitor	12 (41.4%)	7 (7.6%)	<0.001	7 (58.3%)		0.005
Prior user	17 (58.6%)	82 (89.1%)		5 (41.7%)	11 (100%)	
Missing		3 (3.3%)				
Usual engagement with Maggie's Centres for support						
>Weekly		10 (10.9%)				
Weekly		26 (28.3%)			3 (27.3%)	
Fortnightly		7 (7.6%)			2 (18.2%)	
Monthly		23 (25.0%)			2 (18.2%)	
<Monthly		17 (18.5%)			4 (36.4%)	
Missing		9 (9.8%)				

3 | RESULTS

Sample characteristics are summarised in Table 1. Both cohorts had a higher proportion of patient (2019 $n = 29$ [70.73%]; 2020 $n = 92$ [89.32%]) than support network participants (2019 $n = 12$ [29.27%], 2020 $n = 11$ [10.68%]). Most participants were female ($n = 111$, 77.1%), regardless of sub-sample. 2020 support network participants were significantly younger ($p = .010$) but age distribution is generally balanced (total sample: $M = 55.84$; $SD = 10.65$). The most prevalent diagnosis was breast cancer ($n = 58$, 40.3%). 2019 participants were diagnosed significantly more recently: 26 (63.4%) of the 2019 participants took part in the study within twelve months of diagnosis compared to 23 (22.3%) of 2020 participants ($p < 0.001$). A significantly higher proportion of 2019 respondents was receiving active anti-cancer treatment ($n = 22$ [53.7%] cf. $n = 29$ [28.2%]; $p = 0.002$). The 2020 sample was significantly more likely to have visited a Maggie's Centre previously ($n = 93$ [90%] cf. $n = 22$ [54%] in 2019; $p < 0.001$) with 38% indicating at least weekly engagement.

The majority ($n = 88$, 95.7%) of the 2020 patient sample had not had COVID-19 symptoms, nor believed they had been exposed. Half of these participants had been informed about unexpected changes to treatment and/or follow-up since pandemic onset. Of those who responded, 12 (21.4%) were unclear about the reason for changes, 21 (40.4%) were unclear about the implications for treatment-related side-effects, 27 (52.9%) were unclear about impact on survival/prognosis, and 25 (47.2%) were unclear about whether changes were temporary.

3.1 | Unmet needs

At domain level, patient needs were slightly lower after pandemic onset, but only the difference in 'Physical and Daily Living Needs' was significant ($p = 0.001$). Support network participants' needs remained stable, with the exception of healthcare needs which were non-significantly elevated after pandemic onset (Table 2).

Four of the five patient needs that were most reduced fell into the 'Physical and Daily Living' domain, with one other in the 'Care and Support' domain. Unmet patient needs which increased the most fell into 'Health System and Information' (3 items), 'Psychological' (1 item) and 'Care and Support' (1 item) domains. The most increased unmet need was 'being treated like a person, not just another case' (Table 3).

For support networks, the five most improved needs fell into 'Work and Social' (3 items), 'Information' (1 item) and 'Psychological/Emotional' (1 item) domains. The most increased unmet needs related to 'Work and Social' (2 items) and 'Health Care' (1 item) domains, and two items which do not load onto a scoring domain (Girgis et al., 2011). The most increased unmet need related to contributing to 'decision-making about the person with cancer's treatment'.

3.2 | Distress and QoL

Patients' anxiety was significantly lower after pandemic onset ($p = 0.049$), stress reduced slightly though non-significantly, and depression remained the same. Overall QoL was significantly improved ($p = 0.032$), and physical and emotional sub-scales demonstrated large and medium effect size differences (Cohen's $d = 0.81$ and 0.70 , respectively).

Anxiety, depression and stress were all higher for support network participants after pandemic onset, with depression approaching statistical significance ($p = 0.055$). Differences in anxiety were associated with a small effect size ($d = 0.37$), differences in depression were associated with a large effect size ($d = 0.96$) and differences in stress were associated with a medium effect size ($d = 0.76$). Mean differences must be greater than the Reliable Change Index (RCI) to be considered reliable. In the current study, this criterion was met by the lower anxiety in the patient sample and higher depression in the support network sample in 2020, as compared to 2019. No other scales of the DASS were associated with reliable change.

TABLE 2 Descriptive and inferential statistics for sub-sample comparisons of unmet needs, quality of life and distress

	Patient sub-sample					Support network sub-sample														
	2019		2020		ANOVA	2019		2020		ANOVA										
	M	SD	M	SD		M	SD	M	SD											
Unmet needs																				
Psychological Health information	60.09	25.51	50.31	28.00	2.62	0.108	32.64	26.76	30.83	29.61	0.02	0.882	41.61	30.35	39.48	19.35	0.03	0.860	-0.09	
Physical	53.79	25.31	34.37	27.95	10.99	0.001	32.55	24.66	34.38	21.90	0.03	0.858	32.55	24.66	34.38	21.90	0.03	0.858	0.08	
Supportive care	33.08	23.41	25.90	27.44	1.47	0.229	33.13	29.39	45.00	35.69	0.73	0.402	33.13	29.39	45.00	35.69	0.73	0.402	0.38	
Sexuality	29.81	29.27	24.53	32.52	0.55	0.459														
Quality of life																				
Overall	58.76	19.46	66.92	17.07	4.70	0.032	3.34	0.50	2.74	0.47	8.26	0.009	2.75	0.97	2.50	1.07	0.33	0.573	-0.26	
Physical	16.18	6.90	20.75	5.23	13.96	<.001	2.75	0.97	2.50	1.07	0.33	0.573	2.75	0.97	2.50	1.07	0.33	0.573	-0.26	
Social	18.32	6.07	16.29	5.70	2.65	0.106	3.79	1.28	3.40	0.94	0.64	0.432	3.79	1.28	3.40	0.94	0.64	0.432	-0.36	
Emotional	13.07	5.44	16.47	4.69	10.44	0.002	3.39	1.15	2.40	0.93	4.68	0.044	3.39	1.15	2.40	0.93	4.68	0.044	-0.99	
Functional	12.83	5.83	13.57	6.18	0.32	0.571	4.61	0.87	3.87	1.31	2.54	0.127	4.61	0.87	3.87	1.31	2.54	0.127	-0.70	
							3.00	1.16	2.83	1.40	0.09	0.763	3.00	1.16	2.83	1.40	0.09	0.763	-0.14	
							3.04	1.33	2.95	1.26	0.03	0.871	3.04	1.33	2.95	1.26	0.03	0.871	-0.07	
							3.68	0.75	2.50	0.97	9.83	0.005	3.68	0.75	2.50	0.97	9.83	0.005	-1.43	
							3.13	0.93	1.80	0.59	15.13	0.001	3.13	0.93	1.80	0.59	15.13	0.001	-1.77	
							3.25	1.14	2.30	0.95	4.41	0.049	3.25	1.14	2.30	0.95	4.41	0.049	-0.94	
							2.67	0.94	2.85	0.63	0.28	0.604	2.67	0.94	2.85	0.63	0.28	0.604	0.23	
Psychological distress																				
Anxiety	13.21	9.40	9.02	9.79	3.97	0.049	10.55	12.84	15.60	15.49	0.67	0.424	10.55	12.84	15.60	15.49	0.67	0.424	0.37	12.24
Depression	14.86	11.65	14.91	12.76	<0.01	0.985	13.45	11.60	24.67	12.85	4.20	0.055	13.45	11.60	24.67	12.85	4.20	0.055	0.96	10.83
Stress	18.89	9.47	15.32	12.83	1.79	0.183	16.91	10.63	25.00	11.71	2.76	0.113	16.91	10.63	25.00	11.71	2.76	0.113	0.76	9.60

Note: RCI calculated as the standard error of difference between means multiplied by 1.96. Abbreviation: RCI, reliable change index.

TABLE 3 Ranked change in level of unmet need per item between 2019 (pre-COVID) and 2020 (during pandemic) (bold font highlights top five most reduced and increased unmet needs per group)

SCNS-SF34 (Cancer patients)				SCNC P&C (Support networks)			
Item	Question	Rank change ^a	Domain	Item	Question	Rank Change ^a	Domain
Decreased need							
32	Being treated like a person not just another case.	9	Health system & information	45	Having opportunities to participate in decision-making about the person with cancer's treatment.	33	No Domain
33	Being treated in a hospital or clinic that is as physically pleasant as possible.	8	Health system & information	19	Caring for the person with cancer on a practical level, such as with bathing, changing dressings, or giving medications.	31	No Domain
13	Keeping a positive outlook.	6	Psychological	27	Communicating with the family.	24	Work and Social
22	Hospital staff acknowledging, and showing sensitivity to, your feelings and emotional needs.	5	Patient care & support	12	Ensuring there is an ongoing case manager to coordinate services for the person with cancer.	16	Health Care Service
30	Having access to professional counselling (e.g. psychologist, social worker, counsellor, nurse specialist) if you, family or friends need it.	5	Health system & information	21	Adapting to changes to the person with cancer's working life or usual activities.	14	Work and Social
6	Anxiety.	4	Psychological	28	Getting more support from your family.	14	Work and Social
15	Changes in sexual feelings.	4	Sexuality	8	Accessing local health care services when needed.	13	Health Care Service
27	Being informed about your test results as soon as feasible.	4	Health system & information	41	Coping with the person with cancer's recovery not turning out the way you expected.	12	Psychological and Emotional
7	Feeling down or depressed.	3	Psychological	14	Reducing stress in the person with cancer's life.	11	Health Care Service
18	More choice about which cancer specialists you see.	3	Patient care & support	7	Obtaining the best medical care for the person with cancer.	10	Health Care Service
28	Being informed about cancer which is under control or diminishing (that is, remission).	3	Health system & information	9	Being involved in the person with cancer's care, together with the medical team.	9	Health Care Service
12	Learning to feel in control of your situation.	2	Psychological	11	Feeling confident that all the doctors are talking to each other to coordinate the person with cancer's care.	9	Health Care Service
16	Changes in your sexual relationships.	2	Sexuality	13	Making sure complaints regarding the person with cancer's care are properly addressed.	9	Health Care Service
8	Feelings of sadness.	1	Psychological	17	Addressing fears about the person with cancer's physical or mental deterioration.	7	Health Care Service
11	Uncertainty about the future.	1	Psychological	22	The impact that caring for the person with cancer has had on your working life, or usual activities.	6	Work and Social
17	Concerns about the worries of those close to you.	1	Psychological	23	Finding out about financial support and government benefits for you and/or the person with cancer.	6	Information
31	Being given information about sexual relationships.	1	Sexuality	5	Accessing information on what the person with cancer's physical needs is likely to be.	5	Information

(Continues)

TABLE 3 (Continued)

SCNS-SF34 (Cancer patients)			SCNC P&C (Support networks)				
Item	Question	Rank change ^a	Domain	Item	Question	Rank Change ^a	Domain
34	Having one member of hospital staff with whom you can talk to about all aspects of your condition, treatment and follow-up.	1	Health system & information	36	Addressing problems with your sex life.	5	Psychological and Emotional
No Change							
20	Reassurance by medical staff that the way you feel is normal.	0	Patient care & support	2	Accessing information about the person with cancer's prognosis, or likely outcome.	4	Information
25	Being given explanations of those tests for which you would like explanations.	0	Health system & information	4	Accessing information about alternative therapy.	3	Information
14	Feelings about death and dying.	-1	Psychological	10	Having opportunities to discuss your concerns with the doctors.	0	Health Care Service
25	Being given explanations of those tests for which you would like explanations.	0	Health system & information	18	Accessing information about the potential fertility problems in the person with cancer.	0	No Domain
19	More choice about which hospital you attend.	-1	Patient care & support	40	Dealing with others not acknowledging the impact on your life of caring for a person with cancer.	0	Psychological and Emotional
29	Being informed about things you can do to help yourself to get well.	-1	Health system & information	42	Making decisions about your life in the context of uncertainty.	0	Psychological and Emotional
10	Worry that the results of treatment are beyond your control.	-2	Psychological	16	Obtaining adequate pain control for the person with cancer.	-1	Health Care Service
Increased need							
				25	Accessing legal services.	-2	No Domain
				39	Working through your feelings about death and dying.	-3	Psychological and Emotional
				1	Accessing information relevant to your needs as a carer/partner.	-4	Information
				20	Finding more accessible hospital parking.	-4	No Domain
				15	Looking after your own health, including eating and sleeping properly.	-6	Health Care Service
				32	The impact that cancer has had on your relationship with the person with cancer.	-6	Psychological and Emotional
				35	Adjusting to changes in the person with cancer's body.	-7	Psychological and Emotional
				3	Accessing information about support services for carers/partners of people with cancer.	-8	Information
				43	Exploring your spiritual beliefs.	-9	Psychological and Emotional
				38	Getting emotional support for your loved ones.	-11	Psychological and Emotional

(Continues)

TABLE 3 (Continued)

SCNS-SF34 (Cancer patients)			SCNC P&C (Support networks)				
Item	Question	Rank change ^a	Domain	Item	Question	Rank Change ^a	Domain
26	Being adequately informed about the benefits and side-effects of treatments before you choose to have them.	-2	Health system & information	31	Managing concerns about the cancer coming back.	-12	Psychological and Emotional
5	Not being able to do the things you used to do.	-3	Physical & Daily Living	24	Obtaining life and/or travel insurance for the person with cancer.	-13	No Domain
9	Fears about the cancer spreading.	-3	Psychological	34	Balancing the needs of the person with cancer and your own needs.	-13	Psychological and Emotional
24	Being given information (written, diagrams, drawings) about aspects of managing your illness and side-effects at home.	-5	Health system & information	37	Getting emotional support for yourself.	-13	Psychological and Emotional
21	Hospital staff attending promptly to your physical needs.	-6	Patient care & support	26	Communicating with the person you are caring for.	-14	Work and Social
23	Being given written information about the important aspects of your care.	-6	Health system & information	44	Finding meaning in the person with cancer's illness.	-14	Psychological and Emotional
1	Pain.	-8	Physical & Daily Living	33	Understanding the experience of the person with cancer.	-22	Psychological and Emotional
2	Lack of energy/tiredness.	-8	Physical & Daily Living	30	Handling the topic of cancer in social situations or at work.	-24	Work and Social
3	Feeling unwell a lot of the time.	-8	Physical & Daily Living	6	Accessing information about the benefits and side-effects of treatments.	-27	Information
4	Work around the home.	-9	Physical & Daily Living	29	Talking to other people who have cared for someone with cancer.	-28	Work and Social

^a(2020 minus 2019 rank).

Overall QoL was significantly reduced for this sample ($p = 0.009$). Additionally, health care, coping, self-esteem, leisure and social support sub-scales all demonstrated significant and large effect size differences (Table 2).

4 | DISCUSSION

This is the first study to comparatively quantify the psychosocial impact of COVID-19 in cancer patients and those in their informal support networks. Half of our patient sample identified significant changes to their cancer care, with confusion about the implications and temporal nature of such changes.

The current inferential analyses should be interpreted with caution given the small sample size of this study, particularly in relation to our support network sample. Nevertheless, our data, which rely on comparison of psychometrically validated patient-reported outcomes prior to, and during, the pandemic, show that patients' physical and daily living needs have been lower in 2020, as compared to a sample of participants recruited in 2019. We did not find the greater distress and lower QoL among cancer patients suggested elsewhere (Chen et al., 2020; Nekhlyudov et al., 2020). This may reflect the protective effect of engagement with psychosocial care services, however, that does not explain why overall need levels, nor support network well-being, failed to improve. Rather, well-being improvement likely stems from combined consequences of reduced intensity in face-to-face clinical care and physically demanding treatments (Archer et al., 2020), alongside increased home-based informal care provision resulting from lockdown measures and shielding, and telehealth-delivered psychosocial care availability.

This is countered by the higher unmet needs in patients' support networks, which focus on family communication, practical caring tasks and accessing their own support. This group reported increased anxiety, stress, depression and poorer QoL following pandemic onset. The most reduced domain of unmet need relates to work and social settings (activities limited during lockdown) but additional support in coping with the demands of home-based caring pressures is needed (Nekhlyudov et al., 2020).

Four of the top five most increased patient needs related to hospital care and access, reflecting the consequences of reduced face-to-face hospital attendance in view of SARS-Cov-2 transmission risk (Tsamakis et al., 2020). Interestingly, support networks reported high unmet needs related to care co-ordination and treatment decision-making involvement, highlighting the broad-reaching consequences stemming from the discouragement of active hospital attendance.

4.1 | Study limitations

Building on a number of non-empirical, commentary and opinion articles, this is the first systematic comparison of the impact of COVID-19 on psychosocial outcomes in people affected by cancer. Though novel and multi-centre, there are design limitations:

cross-sectional studies lack sophistication, sample size is modest, and our 2020 sample had longer engagement with the Maggie's psychosocial support programme. Given that there were some clinical and demographic differences between these two cohorts, we cannot exclude the possibility that observed differences may be explained by factors unrelated to the pandemic. Some demographic and clinical groups were over-represented in both of our samples which may limit the generalisability of our findings to other populations. The small number of support network participants limits statistical power, however, the medium-to-large effect sizes point to potentially clinically meaningful findings.

5 | CONCLUSIONS

In conclusion, our study shows that the pandemic has led to re-adjustment of unmet needs across diverse domains of psychosocial well-being. Despite not reporting poorer distress and QoL, cancer patients may be relying more on their own support networks to compensate for the lost availability of structured healthcare pathways. As social distancing and telemedicine continue to be promoted as public health strategies to protect the most vulnerable from COVID-19, interventions to support cancer patients' re-organised unmet needs and to address increased carer burden must be prioritised.

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CONFLICT OF INTEREST

DJP received lecture fees from ViiV Healthcare, Bayer Healthcare and travel expenses from BMS and Bayer Healthcare; consulting fees for Mina Therapeutics, Eisai, Roche, Astra Zeneca; received research funding (to institution) from MSD, BMS. All other authors declare no conflict of interest.

DATA AVAILABILITY STATEMENT

An anonymised data set is available by contacting the corresponding author.

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