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Division of
Clinical Psychology
Faculty for Oncology
& Palliative Care – SIGOPAC

GUIDANCE

Psychological insights for cancer services recovery planning

Finding our way

BPS DCP Faculty for Oncology & Palliative Care

Like all in our society and our colleagues in health services, psychological care specialists in cancer and palliative care have been trying to make sense of our recent experiences of the pandemic and to anticipate and prepare for what might come next for patients and ourselves.

This document is for healthcare professionals working in psychological services for people with cancer or receiving palliative care, who are preparing for the 'next normal'.

We draw on psychological models, research findings and collective insights from practice to outline promising responses to the important issues our services are facing:

- 1 An expected increase in the rate and severity of distress experienced by cancer and palliative care patients and their families, contrasting with a reduced rate of referrals;
- 2 Mental and physical exhaustion faced by staff working in cancer and palliative care;
- 3 The psychosocial limitations of socially distanced healthcare;
- 4 A prolonged period until healthcare services 'catch up', and the expectation of further waves of Covid-19 infection and disruptors.

In this guidance we begin by summarising some of the key impacts of the Covid-19 crisis on patients and staff. We then briefly outline a model of adjustment to offer psychologically-informed recommendations to psycho-oncology and palliative care services in responding effectively in the current recovery phase of the crisis.

The Society has produced other relevant guidance on end of life care ([End of life care pathway during Covid-19](#) and [Talking about death: End of life care guidance for the psychological workforce](#)) and video therapy ([Effective therapy via video: Top tips](#)). We would advise readers to consult these resources for guidance on these specific matters.

1. WHAT ARE OUR PATIENTS EXPERIENCING?

People with cancer and those receiving palliative care are reporting particular fear in relation to:

- Treatment disruption;
- Infection risk;
- The health of their families;
- Financial concerns.

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We have also heard from patients who are having difficulty in understanding and trusting treatment decisions, sometimes giving rise to anger and helplessness. Equally, we have heard patients expressing gratitude for professionals who have ‘gone the extra mile’ to deliver their care and offer support and reassurance, and touching concern for them as fellow citizens.

It is plausible that a wave of hidden distress may be revealed in the coming months. We know from previous research that the incidence of mental health concerns increases in crises. Research on general and cancer populations suggests that multiple and chronic stressors exert a strong effect on distress. If these patterns hold in the current crisis, we can expect a significant increase in the incidence and severity of distress.

Some people will have their needs met by the spirit of mutual aid and concern that so many communities have adopted in the crisis; others will be experiencing loneliness and the loss of precious opportunities to live fully. Some patients will welcome and benefit from phone and video interactions; others will feel more disconnected from care, unable or unwilling to engage in these forms of interaction and access to support.

There may be a large cohort of people with cancer who are not being referred for psychological help, but who need it now. Presentations to cancer services have dropped precipitously since the start of the pandemic, in the region of 50 to 80% and new referrals to cancer psychology services have followed suit. There are undoubtedly many people whose diagnosis has been delayed and therefore face a more difficult path through treatment.

Whilst the lockdown is easing now, further setbacks are distinct possibilities in the near future. A second wave of Covid-19 infections may increase the immediate threat of infection and cause another restriction in the availability of healthcare.

The pandemic is expected to result in financial recession and lead to high rates of unemployment. People with illnesses such as cancer are understandably fearful that they are at greater risk of losing their jobs, may struggle to find new work, or feel they will be compelled to put themselves at risk of infection at work, in order to keep their job or to maintain their income.

2. WHAT ARE OUR COLLEAGUES EXPERIENCING?

The experience of health professionals working in cancer and palliative care has many shared elements with that of other health staff, as well as distinct experiences which will not always make the headline stories.

Broadly, these are some of the experiences our colleagues have described:

Collective pride in rising to meet the enormous clinical challenges posed by Covid-19.

Physical, cognitive and emotional exhaustion of rapid change and new ways of working (from restrictive PPE to hours of video-conferencing).

Compassion towards those affected by the deaths and serious illnesses of patients and colleagues, as well as compassion fatigue with excessive exposure.

Anxiety about the threat of infection to ourselves, the risk we might inadvertently transmit Covid-19 to vulnerable patients, and the risk to our families.

Disconnection, not least through shielding, remote working, redeployment, sickness absence, and a diminished sense of achievement, contribution and even identity.

Concern about the peers, groups and communities most affected by Covid-19, for instance elderly, care home residents, people from a BAME background, and people working in particular occupations.

The shadow of moral injury, in relation to the validity of treatment decisions and prioritisations.

Deep concern for patients whose cancer diagnosis may be delayed, and the mounting anxiety of a backlog of unmet needs.

Tension between the need for time to personally recover, and the need to continue to work hard to restore services to patients.

Table 1: Summary of concerns in the 'new normal'

Area	Patient experience	Staff experience
Fear of infection with covid-19	Realistic fears of infection, particularly if coming into hospital.	Realistic fears of infection and of transmitting the infection to others.
Fear of poor treatment outcome	Changes to treatments that may be sub-optimal (e.g. not having neo-adjuvant chemotherapy and proceeding straight to surgery). Changes to surveillance plans that may allow recurrence to go unchecked.	Challenge to core identity and values, sense of control Risk of moral injury in relation to treatment decisions Concerns about legal exposure.
Reduced support and coping resources	Constrained internal and external resources to assist with adjustment (e.g. consistent and accessible staff, social support, jobs & financial resources etc).	Fatigue from changing work practices, and backlog of care Greater stressors at home (eg. caring responsibilities), and reduced access to normal support mechanisms.
Emotion / lost opportunities / restrictions	Facing stark new information that previously seemed distant (e.g. DNAR discussions) Lost opportunity to live life fully.	A greater number of emotionally charged consultations.

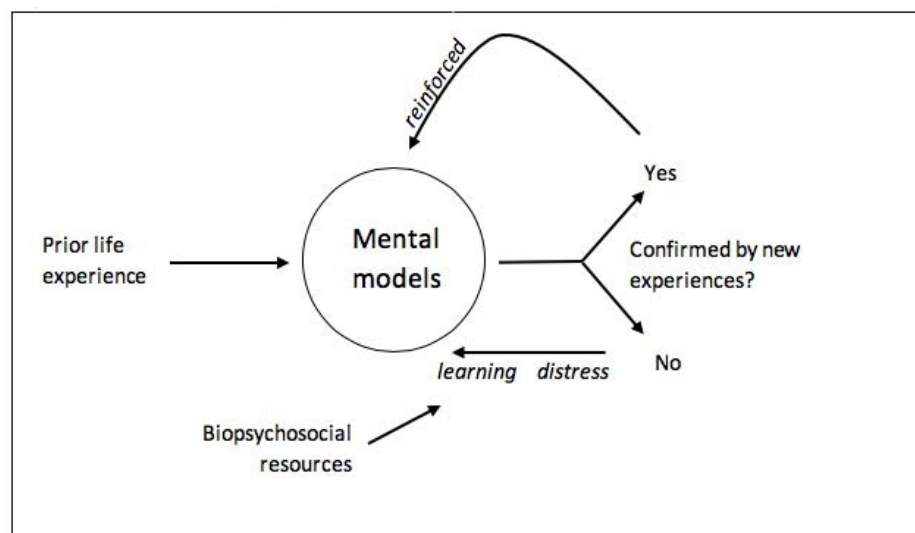
3. AN ADJUSTMENT MODEL AS A BASIS FOR FORMULATING OUR RESPONSE

In the absence of a precedent to guide us, we can draw on psychological models to help us make predictions about how psychological processes are likely to unfold, and to identify actions we can take to usefully shape the processes and outcomes. An adjustment model, combined with awareness of social determinants of health, is highly relevant to our present situation.

As cancer and palliative psychologists, we hear a multitude of different lived experiences of cancer and life-limiting illness. Frequently, people describe the experience of such illness as wiping away existing assumptions of 'normality', taking them on a 'roller coaster' of distressing loss and fear, alongside learning and growth, to a complex and often ambivalent 'new normal'.

As argued by James Brennan (2001), such lived experience is best mapped theoretically to a model of *adjustment* which describes a continuous, iterative process of shaping a mental model of the world through learning from experience. When our existing mental models are 'shattered' by unpredictable and uncontrollable events, disorienting distress and rapid learning can both follow. Given enough support and *the necessary biopsychosocial resources*, this model suggests that people will naturally work through their distress and learn in parallel. This will result in adapted mental models to accommodate this new state of affairs and one's place within it.

Figure 1: Summary of adjustment model.



However, we know that access to support and biopsychosocial resources to support this process is unequal, just as the impact of Covid-19 itself has been unequal. Models such as the Power Threat Meaning Framework can help us to consider how lack of resources or experiences of discrimination and marginalisation on the basis of race, ethnicity, disability, sexuality, gender or other characteristics might affect the adjustment of patients and staff, and help us plan our response accordingly.

The relevance of these models to our current situation is significant. This pandemic has disrupted our working mental models of healthcare 'normality', much like cancer does for individuals. After the adrenalin of the initial 'rally', now comes a long and uncertain phase of restoring a 'new normal', and it's not a confident given that all will have the necessary resources for this adaptation.

4. FROM FORMULATION TO INTERVENTION

This adjustment model allows us a clear theoretical basis to formulate systematic and useful responses to the current situation, despite it being effectively unprecedented. We can broadly anticipate that adjustment and re-orientation will follow if we can supply the right biopsychosocial resources, to both moderate distress and, in parallel, promote effective reflection and learning.

The specific resources and actions needed will clearly vary depending upon the specific service context. Below, we provide an inventory of possible actions and resources for the consideration of services and practitioners, organised pragmatically around the four issues presented earlier.

Of note, much of this involves the purposeful coordination and promotion of existing resources, and practitioners will need to prioritise those actions with the greatest potential impact in their context.

4.1 ADDRESSING AN INCREASE IN RATE AND SEVERITY OF DISTRESS

Overall, it is advisable for services to review their capacity to see a near-term increase in referrals of patients with Level 3 and 4 psychological needs, identify all risks and opportunities for service delivery and discuss these with managers and commissioners. Previous crises have seen increases of between 5 to 20% in general mental health caseness (see service planning appendix for more detailed information).

In direct clinical work with patients and carers:

- a Re-check the person's context and circumstances to ensure their core needs are met (finances, housing, relationships, safety at home, access to medicines and PPE, family health, work etc) even where previously known, and refresh supportive care plans.
- b Consider how the person's experience of the pandemic (and concurrent social movements such as Black Lives Matter) intersect with their other experiences of power, meaning and threat in their life.
- c At an appropriate time, be curious and seek out the person's own sources of resilience: 'How have you kept yourself going? Who has kept you going? What values have kept you going?'

In indirect clinical work:

- a Consider how to systematically facilitate awareness and access to a broad range of digital wellbeing resources for people with cancer, while also considering people who are 'digitally excluded' and will need functional alternatives.
- b Provide additional consultation, training and support for staff in responding to the increased emotional labour in patient interactions, such as feelings of anger and mistrust.
- c Maintain and protect time for Level 2 supervision groups, even where CNS and AHP teams have been re/de-deployed, and maintain emphasis on proactively identifying psychological needs that may be 'hidden' behind practical patient queries.

4.2 ADDRESSING MENTAL AND PHYSICAL EXHAUSTION OF STAFF

- a Create and promote ‘psychologically safe’ spaces for learning and reflection, both operational (e.g. debriefing) and experiential (e.g. Schwartz Rounds, reflective practice groups).
- b Where there are established Level 2 supervision groups, consider where the boundaries can be re-negotiated to give space to personal experience that cannot be safely expressed elsewhere in the workplace, while also maintaining a sufficient focus on clinical practice.
- c Attend to the often ‘silent’ impact of mourning and loss on staff, and consider rituals and ways of marking and memorialising.
- d For psychological services staff, ensure the frequency, focus and medium (video or face-to-face) of team gatherings and supervision are flexibly attuned to current needs; consider using any spare capacity from reduced clinical load to engage staff in fulfilling projects.

Where you can influence:

- e Advocate for continuing enhanced staff wellbeing policies within your own service and the wider organisation, to allow staff to pause and recover (sickness, leave, shifts, breaks, family care) without guilt – this includes psychological services staff!
- f Advocate for staff to be effectively represented and involved in all recovery planning for their services, to maintain a real and ‘felt’ sense of control over their work.
- g Advocate for, model and normalise openness about staff psychological health – for example the ‘it’s OK not to be OK’ campaign, and facilitate access to (and where necessary, deliver) a broad range of staff wellbeing support resources.

4.3 ADDRESSING THE PSYCHOSOCIAL LIMITATIONS OF SOCIALLY DISTANCED HEALTHCARE

Socially distanced healthcare presents challenges to psychological care in cancer and palliative care beyond the technical aspects. There are fewer opportunities for the small gestures of support and solidarity. Non-visible but clinically significant distress is already often missed in clinic and treatment appointments, and this is likely to be magnified in socially distanced services, and more likely to be hidden by a focus on practical concerns.

Psycho-oncology and palliative care psychology services exert useful effects through the indirect influence of being ‘present’ in the medical setting, which de-stigmatises psychological care and is a cue to our colleagues and patients to keep emotions in mind.

- a Review the characteristics of people referred to your service, and evaluate how well they align with the whole population you serve, as well as what is known about the distribution of stressors and resources; collaborate with colleagues to ‘reach out’ to under-served populations, and evaluate these efforts quantitatively.
- b Consider mechanisms for regular, non-intrusive communication with MDT colleagues to ensure presence even when working remotely, e.g. team trainings, operational update meetings, social media.
- c Join colleagues in trainings on new ways of working and offer available expertise in assessment and management of distress through video or phone clinics.

- d Review and update service information and therapy materials to ensure they are relevant to current service provision; for instance, consider guidance to patients on preparing for video- and phone-appointments, and identify tools for collaborative working at a distance e.g. digital whiteboards.
- e Encourage colleagues and patients to connect with peer and collective online networks of support and advocacy (on reputable platforms).

4.4 FACTORING IN TIME TO 'CATCH UP' AND PREPARING FOR FUTURE WAVES OF INFECTION

We hope there will be a timely de-escalation and no further waves of infection. However, we must plan for the eventualities of further lockdowns with further restriction of elective hospital activity, and also the scenario of prolonged high rates of community infection.

Because the effects of health service disruption and the social and economic effects of the crisis will take many months and years to unfold, the relevant time frame for a cancer or palliative care psychological service to plan the response is 6 to 12 months and longer.

Learning from recent experience, consider whether it would be useful to:

- a Develop, and periodically review, risk and continuity plans for psychological care in such scenarios, particularly considering sustainability and staff wellbeing;
- b Review suitability of rapidly-developed self-help materials for ongoing use and different scenarios;
- c Consider individual clinical treatment and risk plans for suitability in different scenarios;
- d Include psychological preparedness as an agenda item in staff support activities.

5. A FINAL WORD

We believe that developing and evaluating our services' responses based on an explicitly psychological adjustment model will yield added benefits, not least to making starkly clear the common human factors that connect patients and staff. While we do hope that this document will soon become redundant, and that the pain will heal, we fully intend for the learning, initiative, compassion, creativity and solidarity that has been nurtured to remain.

Appendix

SERVICE PLANNING

It would be advisable to review the capacity of specialist psycho-oncology services in line with projections for local recovery plans. For instance, in a London cancer network, there are two likely activity recovery scenarios:

- ‘Short dip’ – in which referral volumes recover rapidly between May and July, including presentation of patients who did not visit their GP in March and April;
- ‘Long dip’ – in which there is a more gradual increase in referrals between May and October, before the two scenarios converge.

In the short dip scenario, it is calculated there would be a need to increase capacity by 25% to recover within six months; but in the long dip scenario, this would rise to 75% within six months – and neither can take into account further ‘second wave’ disruption.

While planning for the diagnostic and treatment capacities needed, it would be advisable to consider the additional demand for psychological input for distress, decision-making and issues affecting treatment engagement (e.g. anxiety about attending hospitals, starting treatment).

RESOURCES

Brennan, J. (2001). Adjustment to cancer – coping or personal transition? *Psycho-Oncology: Journal of the Psychological, Social and Behavioral Dimensions of Cancer*, 10(1), 1–18.

Guidance on baseline specifications and capacities for specialist psycho-oncology teams can be found [here](#)

Accessible Kings Fund guidance on leading teams virtually, compassionate leadership in a crisis, and staff experiences of COVID-19

<https://www.kingsfund.org.uk/publications/leading-teams-virtually>

<https://www.kingsfund.org.uk/blog/2020/03/covid-19-crisis-compassionate-leadership>

<https://www.kingsfund.org.uk/blog/2020/06/learning-staff-experiences-covid-19>

Publications from the British Psychological Society

[Power Meaning Threat Framework](#)

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