5.4 Recommendations for providing psychological, social, and spiritual support for patients and their families affected by COVID-19 and those with cancer and chronic end-stage organ impairment whose treatment got limited due to COVID-19 situation:

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IAPC position on providing psychological, social, and spiritual support for patients and their families affected by COVID-19 and those with cancer and chronic end-stage organ impairment whose treatment got limited due to COVID-19 situation:

The IAPC would like to propose following recommendations for providing psycho-socio-spiritual care for palliative care patients and their families affected by COVID-19:

1. All palliative care patients with COVID-19 should be evaluated for distress using validated measures (see annexure 5.4.1). Presence of mild distress can be managed by counseling and psychotherapy. Moderate to severe distress and presence of mental health disorders warrant specialized interventions (see annexure 5.4.1, Table 4 & 5)
2. Presence of red flag signs should warrant immediate referral to a mental health specialist (see annexure 5.4.1, Table 2).
3. Loss, grief and bereavement can be complicated in patients with COVID-19 and can contribute to psychological morbidity. This should be assessed in all patients and their family members and interventions should be initiated early (see annexure 5.4.2, Table 6).
4. COVID-19 can complicate the spiritual concerns in palliative care patients. The disease-containment measures can further worsen the sense of isoloation. It is important to identify and address this as a component of whole-person care (see annexure 5.4.3, Table 7).
5. Stigma is a major challenge in India and has impacted disease prevention, containment, and mitigation strategies. All palliative care professionals need to identify and address stigma during care provision (see annexure 5.4.4, Table 8).
6. Professional and non-professional carers are likely to experience increased stress, anxiety, and moral distress while caring for patients with COVID-19. A coordinated effort needs to be made from the institutions/organizations and teams to alleviate carer distress. Self-care techniques should be taught to all care providers (see annexure 5.4.5, Table 9).

Annexure 5.4.1

Introduction:

The COVID-19 pandemic and the steps to mitigate its spread has far-reaching implications on the mental health and wellbeing of individuals and communities, especially the vulnerable(1). Lancet describes pandemics as the cause and the amplifier of suffering causing illness, death, uncertainty, fear, and socio-economic hardships. The already vulnerable patient in palliative care with either chronic end-stage organ impairment or cancer may experience new psychosocial issues related to COVID-19 situation or worsening of any psychological distress already present. The absence of effective mental health and psychosocial support can increase risk of psychological morbidity in this population(2). In addition, the psychological factors influence adaptation to loss, coping, and adherence to public health measures(3)(4). The various aspects of psycho-socio-spiritual distress and recommendations for management of this distress are outlined below.

Psychosocial Distress:

For most patients with chronic life-limiting diseases, the effects of the pandemic are manifold; one, hospital visits increase their risk of contracting COVID-19; two, if they contract COVID-19 they are at increased risk for severe disease and death(5); three, the nation-wide lockdown has further limited their access to palliative care and opioid medication and has disrupted the continuity of care; four, hospitals deferring elective treatments and appointments in view of the pandemic has impacted the disease trajectory and given rise to uncertainty and fear in this population(6); five, grief and bereavement has become complex in view of the sudden change in the goals of care, multiple losses, and the current physical distancing and shelter-at-place practices(7). While it is important to manage the suffering of severe or refractory COVID-19 infection and end of life anxieties, it is also equally important to address the suffering of the families in isolation or quarantine(8). Denial of dignified after death care has the potential to contribute to complicated grief and post-traumatic stress in caregivers. Given these issues one can expect increased short-term as well as long-term psychological morbidity in both the patients and their caregivers manifesting either as emotional responses (anxiety disorders, depression), or maladaptive behaviours (substance abuse and noncompliance with public health directives)(9).

The normal emotional disturbances in the presence of significant stress include those outlined below(10)(11):

Table 1	
Common Psychological Responses in the context of COVID-19	
Emotional reactions	Worry, anxiety about self and others, sadness, low mood, irritability, anger, reduced interest in routine activities, inability to relax, feeling isolated, guilt if loved ones are helping with daily living activities

Psychosomatic symptoms	Palpitations, aches and pains, trembling and tremor, shortness of breath, sleep and appetite disturbances
Behavioral reactions	Tiredness, disturbed sleep, eating patterns, increased use of alcohol or other substances, acting out, aggression

Table 2
Red Flag Signs: These are the warning signs that when present should warrant immediate referral. If elicited during a conversation, immediately report to concerned authorities.
● Agitation: This can result in a risk of harm to self or others. ● Confusion or Disorientation: Can be due to delirium. History elicitation will include, worsening towards evening, disorientation to time, place or person, agitation, hallucinations, fearfulness, etc. Check for alcohol use ● Substance use: There can be an increase in substance use that can worsen existing mental health problems. Withdrawal symptoms during lockdown, isolation and quarantine could lead to an emergency ● Hallucination and delusions: They can be part of an acute transient psychosis or worsening of pre-existing psychiatric conditions ● Suicidal ideation: Explore for suicidal ideations proactively. If there is a person expressing or seeking help, this indicates a risk and hence immediate referral is warranted if a person seeking help indicates wanting to end life either directly or indirectly, immediate

Table 3
Common Psychiatric Disorders:
● Adjustment Disorders – Emotional turmoil with mixture of symptoms and poor coping ● Anxiety Disorders – Panic episodes, palpitations, tremors, restlessness, irritability, fear ● Depressive Disorders – Low mood, lack of interest, irritability, sleep disturbance ● Post-Traumatic Stress Disorders – Intrusive thoughts, avoiding any reminders of traumatic events, negative thoughts, and emotional reactions

Management of Psychological Distress:

Given the current scenario, psychological crisis intervention strategies need to be integrated into regular palliative care to reduce the psychological damage and provide stability. General principles of management include:

- Most patients present with emotional disturbances in the presence of overwhelming stress. Overlapping of psychological symptoms are common
- Most patients may not have underlying psychiatric disorders. They learn to adapt to the stressor over the course of time with adequate support
- Virtual communication is the cornerstone of any psychological intervention in the context of COVID-19.
- Community-based palliative care organisations/volunteers can play a central role in delivery of psychosocial care.

The steps in psychosocial care is outlined below(10):

Table 4	
Triaging and Psychosocial Care Pathway	
Explore	Therapeutic communication to foster trust and rapport using ● Open-ended questions ● Active and Reflective listening ● Empathetic statements ● Summarization
Screening	Simple, self-rated tools ● Distress Thermometer (DT) ● Patient health questionnaire (PHQ-9) ● Generalized anxiety disorder 7-item scale (GAD-7)
Distress management	MILD Distress (score less than 4 on DT) ● Psychoeducation ● Enhance coping strategies
	MODERATE TO SEVERE Distress (score more than 4 on DT) – ● Psychoeducation ● Enhance coping strategies ● Psychotherapy ● Pharmacological Interventions

Table 5
Psychoeducation – General Steps ● Give reliable information in small chunks ● You may need to quote the source of information if needed ● Keep messages simple and accurate, with repetition, reiteration, and regular checking if needed ● Be honest, give information that you are sure of, avoid false reassurances ● Disclaimer: That we are still learning about the virus and that research is going on, we will update regularly ● Give information to groups of affected people, families, etc. so that everyone hears the same ● Health care workers can become the target of the frustration and anger if people may feel their needs have not been heard or met. In these situations try to maintain calm behaviour and be empathetic
Enhancing Coping ● Ventilation and validation of feelings ● Reassurance ● Maintenance of daily routine, structure ● Realistic goal-setting ● Sleep hygiene ● Maintain realistic hope ● Normalise anger, grief ● Explore feelings of guilt ● Problem solving approach

Psychotherapeutic Techniques
● Cognitive restructuring
  Identification of negative thinking & subsequent emotional/ behavioural response
  Challenging unhelpful thinking through the use of problem solving & testing of negative thoughts
  Coming up with alternative, constructive, more realistic & helpful thoughts to utilize instead
● Thought stopping- adressing negative thoughts, Distraction
● Relaxation techniques, yoga, mindfullness
● Problem solving therapy
● Social skills training

Pharmacological management: (Always with Supportive therapy)

- Consider medications only when the person seeking help has significant distress or behavioral symptoms
- Medications should be considered with caution, weigh it against the risks of medication side effects
- Start at a low dose and titrate slowly as needed
- Drugs of choice for anxiety/depression are Selective Serotonin Reuptake Inhibitors (SSRI's):
  - Escitalopram minimum effective dose is 10 mg/ day and the maximum dose is 20 mg/day
  - Sertraline minimum effective dose is 50 mg/ day and the maximum dose is 200 mg/ day
  - Explain that the beneficial effect of medication might appear only in a few weeks
- SIDE EFFECTS of SSRIs: Nausea, GI upset and headache. In some, SSRI can cause restlessness and insomnia and in the elderly - hyponatremia.
- Medications when needed can be prescribed for a short duration (6-9 months) and then can be considered to be tapered off slowly.
- In view of the respiratory symptoms of COVID-19, shorter-acting benzodiazepines like lorazepam, 1mg – 2mg can be prescribed to lower anxiety symptoms and address insomnia. However, care should be taken to taper and stop the same once the patient is better, as benzodiazepines have addictive potential.
- Agitation, psychotic episodes and delirium could be managed with antipsychotic medications
  - Low-dose haloperidol 2.5mg –5mg per day, or
  - olanzapine 2.5mg –5 mg twice a day, or
  - Quetiapine 25mg – 50mg once a day
- SIDE EFFECTS: There is increased risk of QTc prolongation

Annexure 5.4.2

Loss, Grief, and Bereavement:

COVID-19 pandemic has precipitated a collective community-oriented loss experienced by individuals, families, and society at large. Rapid deterioration in the situation may leave many families unprepared to cope with the loss caused by illness and death, along with loss of sense of safety, financial security, livelihood, personal freedom, and emotional support(12). Changes in goals of care, disruption in continuity of care, changes to end-of-life care practices due to the current situation can complicate grieving process. This can result in anger, guilt, blame, and hostile reaction, especially targeted at the healthcare professionals and systems(13). Bereavement can be complicated, intense, and longer since the event of death is sudden(14). The traditional and culturally accepted mourning practices are not possible in view of infection control strategies and can precipitate complicated bereavement(15). Healthcare workers can also experience unresolved grief and distress. The strategies for addressing grief and bereavement are outlined below:

Table 6
Interventions to handle grief(11)**:**
Target Population: Patients, Families and Healthcare providers
● Normalise the grieving process ● Acknowledge the feeling of loss ● Allow ventilation and validate experience ● Talk about loss and death ● Lead conversation to allow reliving and recall ● Bringing memories of the deceased ● Use support system to reestablish connections virtually with faith, family and community ● Virtual goodbyes and virtual funerals via social media platforms ● Reference to mental health professionals for unresolved prolonged, complicated grief

Annexure 5.4.3

Spiritual Distress:

Spirituality is the way that people seek meaning and purpose in their lives and their sense of connectedness with their inner self, to nature, to the universe and to the transcendent(16). In COVID-19 pandemic, this sense of self, role, and routine is disrupted. The connectedness to nature, universe, and society is threatened. Uncertainty leads to questioning of one's values and beliefs and fosters self-doubt. Pandemics being viewed as punishment for human sins can increase guilt and fear. Spiritual distress arises from the complete loss of hope and a feeling of overwhelming helplessness one experiences in such a situation. The interventions to mitigate spiritual distress in this situation is outlined below:

Table 7
Interventions to mitigate spiritual distress:

● Reestablish Connectedness
  Be available,
  Genuine concern and acceptance
  Active listening to concerns
  Ventilation and validation of concerns
  Reengage within and outside, toward their set of beliefs and faith
● Therapies to foster meaning and purpose
  Dignity conserving care and therapy
  Meaning-centered psychotherapy
  Acceptance and commitment therapy

Annexure 5.4.4

Stigma:

The social stigma associated with COVID-19 is a major challenge in India and has impacted disease-mitigation strategies. Stigmatization has impeded reporting of the illness and has resulted in social avoidance and rejection, physical violence, and denial of healthcare. It has also fuelled attacks on healthcare providers. Dignified end-of-life care and after death care are important tenets of palliative care which have been greatly impacted by the stigma associated with COVID-19. Stigma affects emotional and mental health by creating fear, anger, loneliness, and mistrust. When stigma interferes with utilization of support systems, it leads to alienation and despair/depression(10)

Table: 8
Interventions to mitigate stigma(10)**:**

● Avoid stereotypes, labeling, discrimination
  DO NOT use terms like 'Wuhan or Chinese virus'
  DO use terms like 'coronavirus disease or COVID-19'
● Avoid languages that may tend to dehumanize
  DO NOT use terms like 'COVID case or COVID suspect or COVID positive' or 'infecting, spreading the disease'
  DO use terms like 'the person with COVID-19' or 'contracting or acquiring the disease'
● DO NOT practice social discrimination. DO practice physical distancing; maintain a distance of 1-2 meters. Treat everyone with dignity and respect.
● Provide fact based education programme on how the virus is transmitted, the course of treatment
● Avoid rumours and false news. Correct misconceptions.
● Create a non-threatening platform for addressing the impact of the disease openly. Emphasize the effectiveness of preventive measures and the recovery rates
● Monitor overexposure to social media
● Use supporting narrative and positive stories, especially people in power who have been infected
● Corporate guidelines to respond to those who have been cured of their infection

Annexure 5.4.5

Burnout and Moral Distress among healthcare providers:

The current COVID-19 pandemic has increased levels of burnout among healthcare professionals both by exacerbating pre-existing causes of burnout and bringing about stressors of its own (17)(18). The current scenario has exacerbated the resource crunch and workforce shortage in palliative care. Service provision, team functioning, and communication has been disrupted by new policy decisions regarding physical distancing and infection control(19). Challenging ethical decisions create distress and moral injury when there is dissonance with one's moral compass. Concerns about personal safety and potential mortality, fear of infecting loved ones, limited testing, and lack of evidence-based recommendation for PPE (personal protective equipment) use has contributed greatly to increased stress levels among healthcare providers(20). In addition, healthcare providers experience some degree of guilt and grief, both in the personal and professional domains(7). Mitigation of the symptoms of burnout and distress need a coordinated effort in multiple domains, focused on reducing stress and improving resilience.

Table 9

Mitigation Strategies for Burnout/Stress

Institutional/Organizational Strategies

a) Create healthy environment for workers
   - Provide sufficient resources – PPE, easy access to food and water, cleaning supplies, transportation
   - Manageable work schedules and appropriate breaks
   - Reducing risk for vulnerable by minimizing contact with sick individual
   - Facilitating child and elder care
   - Counselling services for emotional and spiritual wellbeing
   - Provide structured processes in place for care if the healthcare workers get infected (compensation, medical care, rehabilitation)

b) Empower healthcare staff and improve sense of self-efficacy
   - Communicate best practices
   - Relevant and clear evidence-based clinical guidelines and updated information about COVID-19
   - Retrain and enhance medical/ technical skills
   - Clear allocation of resources based on accepted ethical and legal principles
   - Provide a supportive blame-free work culture

Team Strategies:

a) Prepare
   - Clear criteria for triaging the most appropriate patients for palliative care services in the context of COVID-19
   - Train non-palliative care healthcare workers in communication and symptom management

b) Structure the program for responding to the crisis of COVID-19
   - Emphasize team goals
   - Promote shared workload and responsibility for decision making
   - Foster connection and communication to enhance mutual trust to enable sharing of feelings

c) Enhance team wellness
   - Wellness strategies to be embedded in the team meetings
   - Regular debriefing after traumatic incidents – clinical stress debriefing

● Forma buddy systems to enable peer-to-peer connection and to decompress after shifts ● Virtual meeting with staff during periods of quarantine ● Memorial services
<u>Individual Strategies</u> a) Nurture healthy habits ● Adequate sleep, hydration, nutrition, exercise ● Time-outs and breaks at work ● Seek help in dealing with the physical strain of PPE b) Avoid unhealthy coping activities c) Self-monitor and pace oneself d) Foster self-care activities(21) ● Promote a sense of personal and community safety ● Promote calming ● Promote connectedness ● Promote individual and collective self-efficacy ● Instill sense of hope

<u>Conclusion:</u>

Public health emergencies are known to affect psychological wellbeing of the individuals, healthcare providers, and the community and may result in maladaptive emotions, behaviours and actions. Patients with palliative care needs and their families are at an increased risk of adverse psychosocial outcomes. Prevention and management of psychosocial distress is an absolute necessity and would warrant coordinated efforts on the part of palliative care providers and mental health experts and integration of psychological crisis intervention into the general deployment of disease prevention.

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