

Evolving role of the hospice day centre during the COVID-19 pandemic

Hospice day centres are a well-established service in the UK that aims to support people approaching the end of their life to live as well as possible. It functions as a complex intervention working to provide symptom control, psychological, social and spiritual support for patients, as well as respite for carers.¹ The multifaceted role of the day centre aims to improve symptom control through monitoring and timely reassessments and aims to empower patients, fostering a social environment focused on well-being. In the 2008 census of independent hospices and National Health Service palliative care providers published by the National Audit Office, there were 99 hospice day centres seeing 186 patients on average per year.²

Palliative care services have an essential role in the response to COVID-19, with calls for the service to respond rapidly and flexibly to the evolving pandemic.³ The coronavirus pandemic forced the closure of many day services throughout the country. The opportunity to seek the attitudes of patients who have already experienced hospice day services is currently limited due to the pandemic and their perspective is fundamental in guiding services to adapt appropriately to the patient's ongoing needs.

Our local hospice day centre, which usually serves around 160 attendees per month, closed from March 2020 in response to the pandemic. We conducted a semi-structured telephone survey during August 2020 to seek the patient's views about how the service might adapt in the COVID-19 era. Each living patient known to the day centre was rung and consented to completing a standardised set of questions over the phone which covered demographics, diagnosis, previous COVID-19 status, attitudes to the day hospice, how

COVID-19 has affected their attitude towards attending the day centre and free text allowing for exploration of aspects people miss/value most about the day hospice.

Of the 37 patients who attended the day centre in March 2020, ten had died and seven were lost to contact. Twenty patients consented to take part. Attendance history varied from 6.5 to 147 weeks (with an average of 44.5 weeks attended per patient). Principle diagnoses included: cancer (60%), neurological (15%), cardiac (10%) and other (15%). No patients reported ever testing positive for COVID-19, and nine (45%) were shielding following government advice, of whom five lived with someone who was not shielding. Four patients reported they had never left the house during lockdown and a further four patients had only left the house to attend hospital or general practitioner appointments (totalling 40%).

When asked 'Are you anxious or frightened of getting COVID-19?' on a scale of 0–10, 30% (6/20) reported no/mild anxiety, 25% (5/20) reported moderate anxiety and 45% (9/20) reported severe anxiety/fear. Nine out of 13 patients with family reported their family had severe anxiety about the chance of the patient contracting COVID-19. Despite the vulnerable nature of the patient population, the mixed levels of anxiety among the cohort possibly reflect premorbid personality traits and attitudes to risk, as much as self-perceived frailty. This is in keeping with studies from other palliative care units worldwide demonstrating variable attitudes towards perceived risk in this pandemic.⁴

Interestingly, none felt they would benefit from telephone contact despite this forming the dominant method of interacting with these patients during this pandemic. No patients wanted solely telephone contact or for the day centre to close indefinitely. Eighty-five per cent said they would feel happy for a

hospice volunteer to visit them at home. Seventy-five per cent thought it should reopen as lockdown eases, while 35% agreed with reopening the service with social distancing measures in place at reduced capacity. Home visits were favoured over the prospect of returning to the day centre; however, a minority felt they would return with appropriate 'safety measures' in place. This suggests there is no 'virtual' substitute for physical social contact, with the day centre functioning as a fundamental access point for this. This further supports research demonstrating that users benefit psychologically and emotionally from the social aspect of the service.

Patients were asked about whether they wanted virtual group activities; three (15%) patients replied that they did not have a computer. Interest was low (0%–30%) for most suggestions including commonly offered activities such as yoga, mindfulness, breathing exercises or music. A virtual quiz was the most popular with 40% of patients being interested. In case a dislike of group virtual sessions was the problem, patients were asked about one-to-one virtual sessions, again with little uptake. The exception was 60% were happy with a virtual (telephone or video) appointment with a doctor or nurse; and 30% would be interested in telecounselling. Common themes for what patients missed most from the service were companionship: 65% (not including three patients who missed 'everything'); talking about their condition: 10%; and activities (art): 5%. The low interest in suggested activities may mirror patients' interest even when delivered in the usual service face to face. Similar service user feedback was not sought prior to the onset of the pandemic and there may be scope to improve our service's understanding of the preferences of these patients for this complex intervention.

It is difficult to see how gathering frail patients with advanced life-limiting disease for largely social reasons in a group together will ever be legitimate or in their best interest for the duration of the pandemic. This is a great loss for patients and also increases the burden on community specialist palliative care teams. The care and monitoring of these patients inevitably falls to already stretched community services, where a single nurse visits individual patients making this a more expensive service model. In line with many other hospice day services, a virtual service is now offered. Whether this effectively replicates the role of the lost service, or improves it through greater accessibility needs further research.

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