

‘Filtering down psychological thinking into cancer care: that’s how we make a difference’

Sahil Suleman is a consultant clinical psychologist and lead for Macmillan Cancer Psychological Support team at St George’s Hospital in London. Our editor Jon Sutton caught up with him from lockdown...

Everyone on Zoom at the moment explains why they’re tired, but you’re likely to trump me on this: I believe you’re a new parent?

New parent to a toddler, no less... I’m learning some new boundaries, learning that actually work does have to be left behind. The world does keep spinning. But it’s certainly a handful.

How has your work changed over the past year?

Much like many other Clinical Health psychologists in acute physical health trusts, we have been asked how we can redeploy ourselves in a useful way. Many of us have found ourselves helping in staff support, bearing in mind the psychological impact on the whole workforce here, not just ICU staff, not just ward-based staff, shielding staff, everybody really. Certainly within our trust there was recognition that the staff support provision was just not adequate. Most staff, in the middle of a pandemic, were not going to be picking up the phone and seeking a one-to-one therapy session. It wasn’t what was needed. We had to co-ordinate our psychological skills in a different way, at a more systems level, helping the organisation to think through evidence-based ways of looking after organisational wellbeing.

That’s interesting, because we had a piece quite early on in the pandemic, from a psychologist offering that support to staff and surprised by the low take-up; people saying, ‘other people have got a greater need than me’.

It’s ‘hierarchy of needs’ stuff... what people were needing was in-reach psychological first aid, check ins, supporting managers and leaders to be able to look after the well-being of a team that they already knew, as opposed to parachuting in the psychologist to rescue them.

We were emulating what we would normally do in clinical health psychology and within cancer settings: to work with our staff to embed psychological thinking and to apply that to questions like ‘how do I manage the pandemic? How do I continue to feel like I’m providing good care to my patients?’ It’s that sense of moral injury... people struggling to feel like they could care, and give care in the way they would usually want to do.

Then there was more skills-based stuff: what are we using? How can we adapt? How can we change how we communicate? How do we work with families, think about bereavement pathways, check in with junior doctors who were particularly notorious in not coming forward for any of the support.

And in parallel the psychological support service for cancer kept going?

Cancer didn’t go away. Cancer needs were still there. The patient trajectory evolved over time. In the early stages, there was a kind of big full stop panic. Then there were gradual bits of cancer care starting up again and building. We had an

existing caseload of vulnerable patients, we couldn’t just cut them off. Many of these patients were quite risky or were really going to struggle with the double whammy: they had a cancer diagnosis, plus changes in their cancer care associated with Covid. And then ‘how do I live through a pandemic?’

That being said, we did have a quieter patch in that early phase: many of our patients said to us ‘you guys go be NHS heroes, you deal with the hospital’. Patients were very forgiving of all the cancellations and changes in their care early on. Patients were asking staff how they were doing, and sending them care packages. We worried that patients would be angry and upset, but in the early phase that wasn’t there as much. Pockets of it, absolutely. There were naturally

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anxious patients, terrified patients, patients who died prematurely or didn't get the care they needed, or the optimal care. But also a lot of goodwill from cancer patients who just wanted to keep the NHS going.

You didn't feel like at any point the care fell off a cliff?

Certainly not for us. There was probably regional variation in terms of how strict hospitals were about saying 'you absolutely cannot set foot in this hospital', how well-equipped hospitals were to adapt to virtual working and the like. There will be patients that would say yes, in their personal experience it did. But for many it felt like a short-term pause, a sense of 'we'll get through this, we'll get back on track'.

But during that time, many people's cancers did progress, and people did get worse. Coming into the second chunk of the pandemic, we started to see more advanced cancers, where patients weren't seen quickly enough, because they were too scared to come to hospital or go to their GP or because they were balancing risks as, say, an immuno-compromised 70-year-old of walking into a hospital. There were difficult decisions that people had to make, and valid fears people had to weigh up.

There are no 'good options' really, are there? Quite an impact.

We're seeing people virtually, only bringing people in if they absolutely have to be seen face-to-face. We've

had difficult decisions to make, and there have been debates in the news about whether a Covid life is more valuable than a cancer life... it's a messy one.

In terms of your own moral injury around that, is that eased in the context of a global pandemic?

There's no doubt it pushes my buttons when I hear the individual stories of the patients that I work with, or the team bring me stories of the helplessness they feel at not being able to do as much as we would do for our patients... not being able to bring family members in, not being able to work in a holistic way. But perhaps because of the other role I had early in the pandemic, I've seen the bigger picture, I was in the ICU, I can justify what has changed through the 'pandemic-ness' of it all.

The 'pandemic-ness' is quite a thing...

Do you think there will be lasting changes in terms of how you do things as a result of the pandemic?

There are some things where we can't wait to go back to the way they were, not having family members here has been excruciating, patients sitting on wards by themselves, sometimes nearing end of life by themselves, dying by themselves. But also being able to attend appointments with someone... people having bad news about diagnosis or prognosis and having to absorb that by themselves. We adapt, we accommodate things differently. But people are desperate to be able to work in that broader, holistic, family-oriented way.

Are there things we wouldn't mind keeping? Virtual working. For the year prior to the pandemic, it had been one of my key objectives within my team to be able to broaden access to our service by offering virtual working. We know that we have cancer patients who are struggling with mobility, with travel, we have a specialist cancer service that people travel to from quite far away... so I had been looking to set up virtual sessions. They have their own risks in terms of digital divide for those who aren't tech savvy, ridiculous things like the Trust Wi-Fi. But there are patients that I think wouldn't have got to us, or who were more willing to try because they're sitting at home bored in a pandemic.

People who struggle to engage with treatment, to adhere to medication regimens, with decision making... some of the virtual working has actually demystified and broken down some barriers. We were more in our patients' lives. Patients that were very ill and laying in bed and still wanting to have a session, patients nearing end of life that would not have got in... that would be where our input would slowly end, but now we were being a part of their process of dying to a different point.

That had pros and cons: it could feel invasive, challenging, inappropriate. But other times it felt like it was exactly what the patient needed, to hold on to that connection to us for a little bit longer than they otherwise would have done.

So the future is virtual?

On balance, we hate it, it's hard, we can't do our jobs as effectively as we'd like. The hands-on physical work, the felt sense in the room has gone, not to mention all the access issues. People may feel they can continue their life and not privilege the therapy session in a way that sometimes you need to get the most out of it... having their session in the middle of Sainsbury's, perhaps. So there are real downsides, but also aspects we can harness.

Whether it's face-to-face or virtually, what do you see as the cornerstones of psychologically-informed cancer care?

In part, a sense that everybody owns it. It isn't psychology sitting in an ivory tower, and 'oh, there's a depressed patient, a crying patient, it's off to psychology, that's the mental health over there, and the physical health over here'. It's the ability of all of cancer care to be paying attention to psychological need throughout, in parallel, as part of your cancer. Our colleagues should feel skilled and equipped, competent, supported to work with psychological need, whether it be at that more universal level that you'd expect all human beings to experience if facing cancer, or the other end of the spectrum where patients may be getting quite stuck, struggling, or navigating this whole world perhaps on top of existing psychosocial vulnerability and challenges.

Working with our colleagues takes up as much of the work for me as the work we do with patients. Filtering down psychological thinking into cancer care: that's how we make a difference. It's so sprawling as well... we're a tiny team here of four or five people, and cancer care here is 20-odd multi-disciplinary teams, all the different body parts and the cancers that happen in them. We can't be sat with those MDTs all the time, we can't be as present as we'd like on all the wards. We're much better off sharing our expertise, and doing the most complex stuff like the top of a pyramid.

When it comes to patients who are 'stuck', as you say, is there a particular therapeutic model that you use?

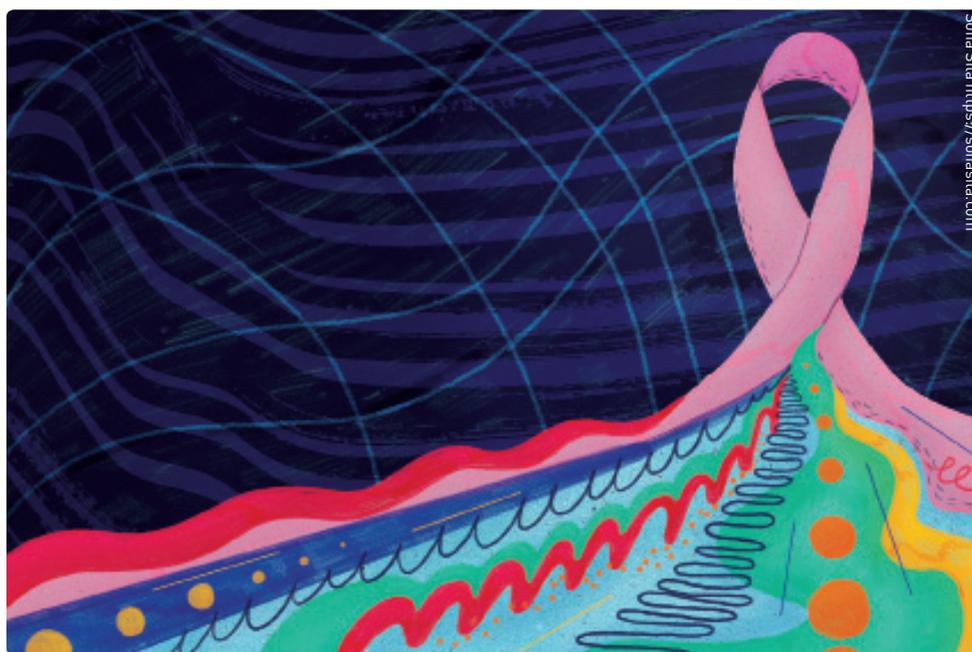
We try to provide choice. It might be individually, working with couples, or broader family work. It might be on wards, it might be in our outpatient clinics, it might be in the cancer clinic alongside the consultants and nurses. Within the one-on-one work, there's a variety too. Clinical psychology, counselling, psychiatrists, all working in this complementary way to ensure the best evidence-based treatment for patients. We're not coming at it from a pure diagnostic mental health model, we want it to be patient-centred and focused more on supporting adjustment. It might be CBT, broader third wave models, ACT, narrative therapy, systemic ways of working, compassion focused therapy. It's about assessing where the patient is that would be most useful to them: that's a real privilege of working in clinical health psychology.

It often seems to me that the higher you go within psychology, to a position like yours, the less precious psychologists become about a particular therapy, or keeping their knowledge as psychologists to

themselves, or just working with psychologists. The best people are the ones who really emphasise multidisciplinary working, and developing a generally psychological approach across the workforce.

You've tapped into a key part of my values. We aren't the arbiters of all the knowledge. Some patients don't want to see a Psychologist, and that's ok! I'm not sure I would be to be honest. Some people will rely more on peers, or our information centre and a more informal chat, some will like a group-based approach, some might write a blog as a way of processing their emotions. Psychology and one-to-one therapy is just one part of a humongous puzzle here. The key is being as accessible as possible to as many people as possible.

It ties in with some of the



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changes we've seen in society, paying a bit more attention to culture and race and to the model we're offering. One-to-one therapy in the ivory tower, is that it? Can we be a bit more creative? We're psychologists, we should be able to think outside of the box, beyond the therapy room. We can work in a system wide way that pays attention to the community, the needs of our local population, the meaning and stigma attached to cancer... all these things are out there and have to be brought to the centre for us to feel like we're doing justice to our patients and to our cancer pathways.

You clearly really feel that duty to the patients.

We're all finding it much harder to be useful to our patients. The core aspects of many therapies are around reactivating patients, reconnecting them with meaningful activities, social connections and social support. All these are things the pandemic has taken away... we've lost so many of our 'go tos' for patients. For many of them, we've become their only contact with the outside world. They're waiting for their therapy call, and they're lonely. That finds its way into us as therapists, feeling quite helpless. I don't think we are immune from these challenges that I've described in our nursing and medical colleagues.

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Psychology is about interaction really, isn't it? That's one of the reasons psychologists have come to the fore over the last year – we're in a good position to explain why people want to get together, how they behave when they do, and the implications of not being able to.

Yes. And I talked about that early phase, where many of our patients were quite forgiving, checking in on us. That's gone. Now our patients are terrified and angry and distressed that things are being delayed again, shut off again, and not having a sense of when it's going to get rescheduled. Our role of psychologists right now in cancer care then becomes about helping to translate that human experience of isolation for our patients to ways in which we adapt cancer care and still ensure it is 'caring'.

But I think we need to evolve as a profession now. If this is how we're working for the foreseeable, do we need to think differently about how we work with our patients and our teams? Ultimately, it's the nurses, it's the doctors, it's the allied health professionals that refer patients to us when they identify the needs. They've been redeployed! The patients have lost their support networks, and we've lost the people out there doing the early screening, picking up psychological needs to get them to us. The need is out there in the community and we can't quite reach it. There's a storm brewing out there... we're ready for that in terms of capacity, but we're expecting the impact of this to be with cancer care for years rather than months. Psycho-

oncology need to be thinking about those adaptation processes, learning and changing how we work as a long-term project rather than a panic response.

Where do you turn to for support? Where do the psychologists go for support?

Often each other. Spaces for us as a group to reflect, to connect with other psychologists locally and across London. My team are really fantastic and it is really humbling to see how they've adapted to the ever-changing way we have to give care, and at times I do wish I could do more to support them. Hearing other services go through similar challenges is also really validating.

I get the impression that personally, for you, it's never going to be enough... you're always looking for better ways to do things.

That's probably a fair description. I don't know if it's a personality thing or the stage of career I'm at, but yes, I don't like looking at a system that is not optimal. There's an appetite for us. Psycho-oncology as a profession is not a new field. We're just the tip of the iceberg in terms of how we can help our patients and colleagues. We could be used

better, we can use ourselves better. There are gaps, and it's not good enough. The pandemic just exacerbated that.

Also, we have seen that there are particular patient groups that we are struggling more than others in the pandemic, particularly teenagers and young adults, 16 to 25. I'm wondering if that's down to how much that cohort relies on peers, and the loss has just been greater for them. Their A-levels, their futures. And there hasn't been a lot of messaging designed by them, for them, which is positive and not blaming. That's important in the context of the new wave, variants... we are finding it affecting younger people more. It's no longer seen as an illness that only affects older patients, which is perhaps how people treated it the first time around.

I see from your sticker you've had your vaccine... are you feeling positive about the route out of this?

It's a long road. I think about how we are going to do right for our patients, but also I worry for my colleagues and how they manage this work. A lot of attention is paid to ICU staff and the frontline, and rightly so. But anybody working in health care has been pushed in different ways.

I've been privileged to be able to feel useful, to keep busy, and to see the trajectory firsthand. So I feel somewhat hopeful, even if I hit periods of exhaustion and overwhelm. In the grand scheme of things, there are periods where we've been able to come up for air, there is movement.