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THE CHALLENGES AND OPPORTUNITIES OF DELIVERING CLINICAL NEUROPSYCHOLOGY SERVICES DURING THE COVID-19 CRISIS OF 2020

Los desafíos y las oportunidades de brindar servicios de neuropsicología clínica durante la crisis Covid-19 de 2020

Os desafios e as oportunidades de prestação de serviços de neuropsicologia clínica durante a crise de Covid-19 de 2020

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ABSTRACT

This short paper describes the effects Covid-19 had on the organization and patient care of a United Kingdom (UK) community brain injury rehabilitation service. The paper is written from a neuropsychology perspective and reflects on the authors' personal experiences of working with brain-injured patients, some of whom were Covid-19 positive, during the crisis of 2020.

RESUMEN

Este breve artículo describe los efectos que Covid-19 tuvo en la organización y la atención al paciente de un servicio comunitario de rehabilitación de lesiones cerebrales del Reino Unido (UK). El documento está escrito desde una perspectiva de neuropsicología y refleja las experiencias personales de los autores al trabajar con pacientes con lesiones cerebrales, algunos de los cuales fueron positivos para Covid-19, durante la crisis de 2020.

RESUMO

Este breve artigo descreve os efeitos que o Covid-19 teve na organização e no atendimento a pacientes de um serviço comunitário de reabilitação de lesões cerebrais do Reino Unido (Reino Unido). O artigo foi escrito sob a perspectiva da neuropsicologia e reflete sobre as experiências pessoais dos autores de trabalhar com pacientes com lesões cerebrais, alguns dos quais foram positivos para Covid-19, durante a crise de 2020.

Introduction

Early in 2020 a frightening new disease started to spread around the globe. By the end of March 2020 many countries were in lockdown, with infections and deaths mounting every day. Everyone knew the name of the illness dominating the international news: Covid-19. This novel coronavirus was causing social, economic, and existential havoc. Fear spread like a bow wave ahead of its progress. Comparisons were made with the Spanish flu epidemic of 1918, and other great plagues stretching back to antiquity. The public quickly became versed in new concepts like ‘flattening the curve’, ‘herd immunity’, and ‘R₀’. At least in western populist culture, expertise had become increasingly derided, but now epidemiologists and chief medical officers had become the new rock stars. World leaders and policy makers had impossible decisions to make: choosing between economic ruin and the resultant high death toll in the long term, or overwhelmed hospitals and the resultant high death toll in the short term. Most chose the immediate protection of life. So, healthcare providers had to adjust, and rapidly.

The imperative was no different for clinical neuropsychologists, and brain injury services: we had to alter fundamentally the way in which we delivered care. In this paper we reflect upon our personal experiences of working as clinical neuropsychologists during the Covid-19 crisis, as well as how our patient interactions have changed, and the support we have tried to give staff. We must empathize though that our experiences were not the only – many of our colleagues in the service experienced the same, or more profound, conditions. But, firstly, we describe the organizational challenges for our service: an NHS (National Health Service) community brain injury rehabilitation service in the UK, described in greater depth elsewhere (see e.g. Coetzer, 2008). A word on context: this paper was written late April 2020, when it appeared the UK may have passed the (first, possibly) peak, and critical care capacity had not been exceeded. Just as the models predicting the spread of disease have had to be adjusted continually, so it is likely our service may have to make more changes in the future in response to Covid-19’s shifting course. We hope therefore that our readers will take this into account; our paper is not intended as gospel on how to pandemic-proof a community brain injury service.

Organisational challenges

Very soon after the lockdown was implemented in the UK, hospitals stopped providing most of their routine outpatient appointments, as well as non-essential surgery. The day-to-day situation transformed rapidly within clinical services. Initially logistical issues dominated, such as making sure the service had enough personal protective equipment (PPE) to let us safely see patients with acquired brain injury (ABI). A system had to be devised for seeing patients who needed community visits, in particular those who had been discharged early from hospital, or existing patients in urgent need. Firstly, we had to manage the risk to patients. In the absence of access to Covid-19 testing during the early stages of the crisis, clinicians had to screen themselves for symptoms prior to seeing community-based patients, not least because many of us were by this point also

working in inpatient settings where the infection was present. In terms of the risk to our team, a telephone-administered screening tool for Covid-19 symptoms was developed for use by all staff prior to any visit. High-risk clinicians – those with underlying medical conditions which increased their vulnerability to Covid-19 - could not come to work, as they had to self-isolate. Additionally, where anxiety about patient contact (for self or family) was deemed to preclude direct patient work, team members were encouraged to work from home, or from within the unit whilst maintaining social distancing. These two factors approximately halved the workforce available for direct patient work.

Not everything posed an obstacle. An unexpected positive outcome during the crisis was that non-essential bureaucracy decreased and decisions about patient care could be made at speed. Travel to other hospital sites or patients' homes became quicker, as there were almost no cars on the road due to the lockdown. The origin of referrals to the service changed, with many more now coming from inpatient settings. Some of these were what, in normal circumstances, we might have described as premature discharges, but this had been deemed the 'least worst' option when it came to guarding against hospital-acquired infection. Our system of referral prioritisation also changed, and was now performed daily, rather than weekly. Once referrals were allocated, clinicians had to screen those living in the community to determine if a home visit was required, given patients could no longer attend clinic. If indicated, PPE had to be used during these home visits, otherwise social distancing and meticulous hand hygiene were used to reduce risk to clinicians and patients. Overall, the speed of clinical decision-making increased, which most likely had some positive effects on patient care during the crisis.

For those for whom a home visit was inappropriate, we explored other ways to offer consultations. These included telephone follow-up appointments, telephone screening, and video calling. Video calling provided substantial challenges. Commercial paid-for video conferencing software failed to link reliably, or at all, with the free, much more effective software widely used by most of our patients (and ourselves in our non-professional capacity). Concerns about software security, patient confidentiality, and suitability for use by our patients, were some of the initial obstacles to overcome. Both telephone and video calling were also difficult for many of our patients depending on the nature of their cognitive impairment, and for that significant proportion with dysphasia. For some patients, we resorted to old-fashioned written communication, exchanging letters or emails. This was another unexpected positive outcome: for some of our clients with slowed speed of processing, this actually led to more reflective and constructive 'conversations'.

At an early stage of the crisis a decision was made within the service to start to think ahead about a potential 'lost to follow-up' problem from occurring. Patients who were due for routine review were written to and informed that these appointments were cancelled due to Covid-19, but that they could still access the service remotely. Our central administrative assistant was tasked with meticulous record-keeping: which patients needed new appointment letters, and when, once the crisis was over. Without these data, reorganising future clinics would have become a logistical nightmare. However, delivering care to patients while in the midst of the crisis was a more pressing need.

Patient care

Let us first reflect on the significant challenges the neuropsychologist faces when seeing neurological patients for an assessment on a Covid-19 isolation ward (see also Coetzer, 2020). For a start, it takes more time. Changing into theatre scrubs, fitting PPE, removing it precisely in reverse order, and showering upon leaving the ward is a protracted process. Arriving early at the ward is therefore important, but this still means fewer patients can be seen for a neuropsychological opinion during a ward visit than would normally be the case. There are also surprises which await the neuropsychologist, some of which may, with hindsight, be obvious. Infection control measures naturally prevent making notes: a jotter would pose a contamination risk. The clinician therefore has to hold an entire assessment in mind, accurately, so they can record the details outside. The same rationale also prevents deploying paper and pencil tasks (e.g. the Montreal Cognitive Assessment; Nasreddine, Phillips, Bedirian, et al., 2005). Even if wristwatches were permitted, these would be impossible to see underneath PPE. In administering, for example, a semantic fluency task, the clinician is faced with trying to count seconds ('one elephant, two elephants...') at the same time as attending to the words being produced, which may well include 'elephant'! Speaking through a mask to patients who might have hearing or processing impairments from their injury also makes bedside testing hard. Moreover, one discovers very quickly that wearing PPE is claustrophobic and hot. Leaving the ward, one feels drained, dehydrated, and headachy. Sometimes there is also the nagging sense that the assessment has been sub-optimal.

Factors related to Covid-19 itself, such as the severe viral fatigue experienced by many patients, can impact the findings of bedside cognitive testing. Patients may only be able to tolerate short sessions, and their performance may be artificially

impaired. The decisions to be made based on these assessments can, however, have significant implications. This adds to the stress of trying to disentangle what is behind the observed underperformance: Covid-19 symptoms, ABI, or both. Accordingly, an awareness of issues pertaining to reliability, validity, and interpretation of results under these circumstances is crucial.

For both community and hospital patients we saw, from the start we became aware that psychological factors associated with the Covid-19 crisis can also affect our patients' phenomenological experience and mental health, irrespective of whether they have the illness or not. Covid-19 is a frightening new disease, which has caused severe disruption to people's normal routines, socialising, and communities. When seeing patients, anxiety about Covid-19 can influence their presentation over and above that normally associated with their brain injury. In the ward environment, and for some community-based consultations, this anxiety can be exacerbated by the challenges associated with wearing PPE, which prevent the clinician from building a calming, therapeutic rapport. At the most basic, but crucial level – they cannot see our smile. Many of these issues also pertained to working with non-coronavirus patients in hospital. A combination of reduced community workload – our efforts at alternative access notwithstanding – and a felt moral imperative to be where we could be of most use, had led to some clinicians proactively suggesting they temporarily move to inpatient roles, working on nearby stroke wards. This was suggested to our local hospital consultants, who were eager to accept. Our objectives were threefold: to facilitate quick assessment, rehabilitation, and discharge, safely away from the risk of hospital-acquired infection; to build advanced knowledge of the patients who would become 'ours' in the community; and to use the opportunity to embed ourselves in acute teams, thereby providing informal teaching and consultation.

There are many neuropsychologists who are aligned with inpatient ABI services in normal times, but these were definitely not normal times. Patients had to be treated as suspected Covid-19 cases until swabs proved otherwise. There were positive cases in neighbouring wards. Some members of the ward clinical team unfortunately despite best efforts to stay safe, contracted the illness, and sadly, elsewhere a death of a clinician occurred. Covid-19 was therefore a very real, almost visceral threat. Although some of the rules were less restrictive than on the Covid-19 wards, allowing us, for example, to carry pen and paper, we still had to wear masks, which made communication hard, both in terms of giving reassuring, non-verbal signals to patients, but also it hampered comprehension for those reliant on lip reading and other cues. After each patient was seen, we had to leave the ward, dispose of masks and gloves safely, wash hands, and don new PPE, before returning. PPE was also necessary when consulting with colleagues, if we could not be two metres apart, which was the case in some ward rounds and multi-disciplinary meetings. An average day saw some of us get through many sets each.

Covid-19 also had indirect effects. There were no visitors allowed in the hospital, and it is likely this will have had a deleterious effect on patients' mood, their rehabilitation, and our own understanding of their history and the course of their illness. Decision-making became expedient and carried high stakes. Given many nursing homes were in lockdown themselves, with reduced staff, and not accepting referrals, patients who would have benefitted were instead sent home. The majority of social workers who would normally assess patients on the ward in order to put person-centred care packages in place were working remotely. At the same time, there were other patients whose families did want them home, at least to see if and how they would manage. In different circumstances, this is something we could have facilitated, as the patient could have transferred into a nursing home if and when the family decided they could not cope. The climate during the crisis was such, however, that we could not guarantee future placements, nor decent levels of support for the family, and therefore urged them to place their loved one in a nursing home straightaway. With nursing homes not accepting visitors either, this created a situation where patients we had seen, might die without families having been able to say goodbye. This was a very distressing experience for us.

While in the community seeing patients, we worked in the presence of anxiety, while working on the wards, death. It is obviously not unusual within neurological clinical populations for patients to be placed on end-of-life pathways sometimes, receiving palliative care. But Covid-19 compromised some of that pathway, and meant that suffering was not universally eased. For example, patients could not be transferred to a hospice for the compassionate care they and their families would normally have received. Nor could many of them have a private room, given these were needed for infection control. Thus, we had the situation where people who were potentially terminally ill with Covid-19, on open wards next to other stroke patients, some of whom were cognitively able. This was deeply distressing for both patients and staff.

Staff support

We took the opportunity to put in place formal and informal psychological support for our colleagues on the wards to address both this and the multitude of other difficulties. This support featured simple acknowledgement, validation, and containment of their thoughts and feelings in reaction to Covid-19, as well as more formal, timetabled mindfulness training. These sessions were gratifyingly well-attended. Colleagues spoke of the blurring of work and home, given the threat of Covid-19 was also very present in the latter. The lack of traffic led to shorter commutes, but this also meant less time to process the day's experience, and to switch from professional mode to personal. Like us, they were experiencing increased cognitive load, and fatigue, but ongoing anxiety rendered sleep difficult. We helped normalise these reactions, and modelled being open to difficult thoughts and feelings, including this sense that we were not always able to give the level of treatment we would want.

Supporting the clinical and administrative staff in our own service also posed particular challenges. Regular communication was important, to mitigate against confusion and misinformation. Pastoral care for clinical staff was key to their being able to continue to care for their patients in turn, under very difficult circumstances. This was made harder by the fact that, with some team members isolating, some working from home, and some now ward-based, we had become geographically dispersed. Colleagues unsurprisingly spoke of fear when working directly with brain-injured patients who had suspected or confirmed Covid-19. Some reported hospital-based dreams. Interestingly, a universal theme was that 'down time', or waiting for referrals, was more anxiety-provoking than actual patient contact; the same 'eve of battle' feeling we experienced when preparing for Covid-19's onslaught. Seeing neurological patients on an isolation ward and then returning to community work, appeared to have a 'two-spike' anxiety effect: not only during the ward visit, immediately after which there was some reduction in anxiety, but also once the window of potentially starting to experience Covid-19 symptoms commenced a few days later. That same 'sense of something frightening about to happen' that we often screen patients for when checking on mood.

Personal reflections

We would like to emphasize that the authors' experiences and our clinical work during the crisis outlined in this paper were not unique. Many of our colleagues in the service experienced the same, or even more of what we did. And of course elsewhere in the hospitals, other health professionals working full-time on Covid-19 isolation wards, were much more severely affected by the crisis. For us the Covid-19 crisis has been hard, and prompted much reflection, some of which has been precisely about this shared experience, with both colleagues, and of course, our patients. After years of urging our patients to tolerate uncertainty, we have had to cope with it ourselves. At the time of writing, we did not know when it would end, advice changed constantly, and we had to practice the psychological flexibility we preach.

Health anxiety might be something we include in a patient formulation, but now we were similarly hyper-vigilant: was that cough persistent, was the taste of that sandwich I just ate muted, am I feverish, or just overheating in my PPE? Often we felt helpless, of much less immediate use than our medical and nursing colleagues. Our self-efficacy at times was dented by this, and by the restrictions which meant we could not always execute our roles in exactly the way we would like. Decisions had high stakes, and had to be made despite being cognitively and emotionally fatigued. And everywhere the existential threat: for our patients, our colleagues, our communities, ourselves, our families. It is difficult returning home to partners, family members and children eager for a hug, when you know that you are something of a disease vector, potentially escorting a deadly intruder through the front door.

So, it has been the worst of times, but it has also been the best. We were struck by the gratitude of our patients when we saw them, and of our country towards those who have continued to care. There has been a reduction of the gap between clinician and patient: we are in this together. A sense of common purpose and cohesion, not just with our colleagues, but at a national, and even global level. There have been some changes to the way we work, which, though expedient, are potentially of long-term benefit, like the closer relationship with our acute medical colleagues, and the rebirth of the old-fashioned therapeutic letter. Predominantly, despite often feeling powerless, overwhelmed by the loss around us, and exhausted, we have found caring for patients and supporting staff through this pandemic a humbling, even inspiring, experience.

Conclusions

Covid-19 has posed many challenges to the care our service provides to patients with suspected or confirmed neuropsychological difficulties. During the ongoing crisis our service continues to receive requests for the cognitive assessment and rehabilitation of these patients, to help inform their ongoing care. In fact, in our experience there are increased demands, given necessarily premature discharge. In the community, this has required rapid adaptations to the way we work. On the wards, conducting cognitive assessment under the restrictive conditions imposed by Covid-19, and without our normal tools, or in the community doing domiciliary visits, has required a flexible approach. Allowing extra time for our consultations is important, as well as accounting for non-cognitive factors, in particular anxiety and fatigue. Despite the challenges stemming from the Covid-19 crisis of 2020, our patients cannot be deprived of the clinical work, albeit now adjusted, which now as in the past, remains important for their care and rehabilitation. Although the future is unsure, given an early study has already evidenced the neurological impact Covid-19 can have on patients, we may be seeing many more cases in the months to come (Ling, Huijuan, [Mengdie, et al, 2020](#)). Overall, the Covid-19 crisis has been a formative experience for us. It has reconfirmed why we chose this profession, has counterbalanced challenges with opportunities, and will very likely have significant effects on how we care for our patients in the future.

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We thank our colleagues in the North Wales Brain Injury Service who, under very difficult conditions, and with the courage that is integral to compassion, continued to care for the people referred to our service during the Covid-19 crisis of 2020. We also thank our patients and our communities for the gratitude and support for our work they showed during the crisis – we will never forget this.

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