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Of care, cure and the in-between: COVID-19 treatment in a New York City intensive care unit

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Through historical division of roots in the field of medicine, care and cure became positioned at opposite extremes. In this article, we merge conceptual framings with empirical data to consider how the dialectic between caring and curing shaped understandings during the spring 2020 wave of COVID-19 infections. We utilised interviews obtained from healthcare clinicians of a medical centre who volunteered in New York City during the surge of 2020. In the analysis, we reflect upon examples to illustrate how the unpredictability of COVID-19 temporarily deconstructed hierarchical boundaries between caretakers and highlight the benefits of incorporating palliative care measures in COVID-19 treatment.

Key words palliative care • health • quality of life • health and social care professionals

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Introduction

Care is ‘an invisible glue that holds society together’, writes psychiatrist and medical anthropologist [Arthur Kleinman \(2020: 236\)](#) in his latest book, *The Soul of Care*. Yet, while invisible to some, care can present a tangible, visceral and visible reality to those experiencing COVID-19-related symptoms, both during and after illness. Indeed, it may be the perceived invisibility of care that caught our health systems unprepared. In the face of an event unlike any global crisis in recent history, those systems became unglued and, at times, proved underfunded ([Bearman et al, 2020](#)), inequitable ([Scheerens et al, 2020](#)), fragmented ([Lal et al, 2021](#)) and insulated ([De Ceukelaire and Bodini, 2020](#)). These dire circumstances sparked a deep yearning for a cure. However, the advent of a new aetiological agent is coupled with uncertainty

and ambiguity (Durodié, 2020). Illness can remain an indistinct term, with a focus on the risk of falling ill, besides the necessitation of active disease symptomology. The handling of COVID-19 – like other illnesses – can come to be something to undertake even when active illness may never manifest (Taussig et al, 2013). With no curative treatments for the new coronavirus infection itself and vaccines still not widely accessible, we mainly placed our focus on trying to avoid an infection. For those whose infection posed a fatal threat, approaches were nested within symptom-modifying and life-preserving therapies in the hope that with enough time and proper medical and social support, the body will survive and restore its systems to prior function. Without an immediate cure, care, in all its forms and guises, became paramount. Care became visible.¹

In this article, we build on literature from medical sociology and history to discuss the explicit and implicit effects of a care-cure dichotomy. In particular, we consider how historical and present-day definitions of care and cure may have affected the experience of intensive care unit (ICU) personnel. The analysis merges conceptual elements and framings with interviews obtained from nine healthcare practitioners of an academic medical centre in California who volunteered in New York City during the spring 2020 wave of COVID-19 infections. As we will see, with no cure at our disposal, the concept of care, with all of its complexities, took centre stage as an emerging hallmark of the pandemic (Arabi et al, 2020). It also brought out from the shadows pressing questions that had arisen long before the pandemic's arrival, tying the pandemic to a larger discourse on caring for patients with other disorders with no cures in near sight (Krause and Boldt, 2018; Abrams and Abbott, 2020). Will the pandemic change the way we approach conditions without cures (Berghs, 2021)? Will it transform how we administer care (McPeake and Pattison, 2020)?

The article is organised into four sections, combining both conceptual and empirical elements. First, as a conceptual segment, we introduce a historical note on how notions of care and cure became polarised. Correspondingly, two divergent philosophies of care and cure have carried over to today's predominant healthcare systems and structures. Second, introducing interview segments, we reflect on how the dialectic between caring and curing may have shaped understandings and practices in New York's COVID-19 wards, and how both physicians and nurses made sense of the unprecedented severity of the pandemic. Third, we reflect upon examples to illustrate how the unpredictability of COVID-19 temporarily deconstructed organisational and hierarchical boundaries between caretakers. Fourth, we highlight the benefits of incorporating palliative care measures in treatment, not despite, but because of, COVID-19's uncertain recovery parameters.

Conceptual segment: the shared roots of care and cure

By tracing the term 'cure' to its origins, we find that the concepts of care and cure are interwoven, as, tellingly, the derivation of the English word 'cure' stems from the Latin root 'cura'. In early Latin literature, the word 'cura' conveyed two root meanings, implying conscientious attentiveness and affection, on the one hand, and worry and anxiety, on the other (Burdach, 1923). The Graeco-Roman myth of 'Cura' powerfully illustrates the contradictory relationship between the two connotations: care as devotion and kindness; care as weight and liability (Grant, 1960; Hyginus, 1976 [1535]). The ancient allegory conveys the perception that care is fundamental

to our humanity and reflects the central and holistic view of care in classical antiquity. Care begins even before our embodiment, before our spiritual awakening, and stresses the enormous value it provides to human life (Grant, 1960; Shklar, 1972; Reich, 1995). In several pre-modern medical traditions, care and cure similarly overlapped. In medieval Europe, secular and religious practices were both applied to heal maladies of the body and spirit (Conrad et al, 1995). Prayer and medicine were drawn on in equal measure; their fabric was often woven together. As Western medicine transformed into a more empirical discipline throughout the 19th and 20th centuries, medical practitioners progressively concentrated on caring for and curing the body, and left the realm of spiritual care to the clerics. 'Healing' remained a widely applied term, with many definitions and usages. Authoritative lexical sources attribute the origin of the word 'care' to the Anglo-Saxon word 'caru', which implies anxiety or worry (see also Fine, 2004). Meanwhile, as its own linguistic entity, the English term 'cure' was borrowed from the French 'curer' (from the Medieval Latin 'curatus' – 'one responsible for the care (of souls)' – from the Latin 'curatus', past participle of 'curare' – 'to take care of'), though eluding some of its various care-oriented connotations in the process. The distinction between the two concepts evolved alongside medicine's growing cultural authority, ushering in a paternalistic medical model in the 19th century (Lachmund, 1998). The discovery of antibiotics in the 1930s further fuelled this development, saving millions of lives and laying the groundwork for both biomedicine's modern scientific framework and a vast new industry known as 'Big Pharma' (Rosen, 2017). The idea of a cure was well received within medicine's hegemonic heroic narrative and propelled the move towards ever more specialisation (Weisz, 2006). Curing steadily came to be a measurable method, device or medication that restores good health after disease or reinstates soundness after injury. Care, in turn, remained a continuous, ephemeral task that occurs beyond a measurable baseline of normal function. Physicians cured biological ailments, applying biomedical, mechanistic reasoning. Their governing paradigms were directed at infectious diseases, administering acute treatments. The responsibility for care primarily fell to nurses, family members, spouses or friends, who were concerned with matters of healing. What began as a predominantly heuristic distinction led to a division into two ostensibly separate principles and disciplines. Today, practices of caring and curing often still presuppose a duality when, in actuality, the concepts are intimately intertwined. Most strikingly, this is reflected in the realm of medicine – a *cure*-oriented field existing within the *healthcare* sector, as opposed to the *diseasecare* sector.

Modern medicine has produced remarkable advances in the treatment of numerous diseases. Within an exclusively curative focus, however, little room remains to consider the significance of environmental, social and cultural contributions. Rather than through targeted medical interventions, the modern world's population growth, for instance, has been significantly aided by wide-ranging social and economic changes (McKeown, 1976; Grmek, 1990). Likewise, the improvement of health standards was primarily a result of public health measures (Porter, 1997). In the meantime, various purely curative methods have become ill-equipped to cater to the needs of the patients with chronic disease these same methods groomed. Moreover, the social study of health and illness has shown time and again how the contours of normalcy are far from fixed, and it is not uncommon for definitions of what it means to be ill, and, accordingly, what it means to be cured, to shift (Hausermann, 2017). As actors in the medical field seek quantifiable, solution-oriented and preventive action, being at risk, in itself, can move an individual into a space of illness requiring treatment

Table 1: Respondent characteristics

Profession	Clinical background	Years in practice	Age	Gender	Ethnicity
5 physicians (all doctors of medicine [MDs]) 3 registered nurses [RNs] 1 nurse practitioner	Critical care (7) Cardiology (1) Anaesthesia (1)	7 to 24 years (mean 12 years)	Mean age 39 (33 to 51)	Female (6) Male (3)	Asian American (3) Multi-ethnic (2) Non-Hispanic white (4)

(Scott et al, 2005). Additionally, a purely curative model often cannot adequately address the needs of patients who experience acute or chronic diseases for which a cure is elusive and where the quality of interim care may be the only thing separating them from poorer or better outcomes. COVID-19 offers a salient example, and in the following sections, we will see how this dynamic played out in New York City's COVID-19 wards.

Methods

In June 2020, one of the authors (Elizabeth Dzung) conducted semi-structured, in-depth interviews to document the experiences of volunteers and nurses from a California academic medical centre working in ICUs in a New York City academic medical centre during the initial COVID-19 surge (April to May 2020). These critical care doctors and nurses had volunteered for a month-long assignment. The respondents were recruited through email and nine participated in the interviews (see Table 1 for participant characteristics).

Interviews were conducted over Zoom, lasted between 40 and 60 minutes, and were audio-recorded, anonymised and transcribed. The transcribed text was analysed iteratively and in two phases, first deductively and then inductively (Fereday and Muir-Cochrane, 2006). In a first phase, two researchers read and reread the interview transcripts in order to obtain a broad understanding of the participants' experiences and selected quotations that fall into the purview of the care-cure discussion. Thereupon, thematic analysis was used to identify prominent patterns in the data, applying professionals' experience of the pandemic as personal reflections on the conceptualisations of care and cure. No remuneration was given for participating in the interviews and ethical approval for the study was granted by the research centre's Institutional Review Board.

Empirical segment: results and interpretation

New York City was hit particularly hard by the first COVID-19 wave. In parts of the metropolis, every third person was infected with the virus and the high death rate was partially the result of an overloaded healthcare system. The city had weathered other crises; the morale of healthcare professionals and first responders during those times was crucial to the survival of the city (Chokshi and Katz, 2020). Yet, the virus created a situation that was rare in modern times, as we have typically cared for people who have non-communicable disease or communicable illness that is difficult to contract. This difficulty of caring in the context of a highly contagious pandemic contributed to the disruptive effects. It presented unique logistic and moral challenges that stretched the capacity of hospital professionals. As of June 2020, no approved

medication therapy existed. The World Health Organization (WHO) endorsed supportive care only, and healthcare systems had to maintain a reasonable balance between treating acute and chronic factors (Song et al, 2020). A majority of patients who were hospitalised exhibited a high prevalence of diabetes, cardiovascular disease and hypertension, suggesting an important relationship between these underlying conditions and increased severity of illness. In turn, other patients without pre-existing co-morbidities could also be severely affected. Given the novelty of the virus, creating safe, standardised processes proved extremely difficult, and the progression of the disease was unpredictable at best.

Between fighting and saving: the ICU experience

One example concerned the practice of intubation. Initially, early mechanical ventilation was considered a crucial, lifesaving treatment. Yet, critical care physicians began questioning the widespread use of the breathing machines. As one MD described the practice of intubating patients for weeks at a time:

‘It became the new normal: that it’s okay for somebody to be on the vent for two to three weeks, not even well enough to be trached.... I think in my past experience, if somebody had been on the vent for three weeks with minimal sign of improvement, we would’ve been attempting to guide the families more towards a palliative approach.’ (ICU_MD_1001)²

Indeed, COVID-19 demanded new treatment protocols, forcing medical providers and patients to rapidly adapt to changes and unpredictable scenarios. One MD, resorting to war metaphors, vividly portrayed their impression upon entering what would become their work area for the upcoming weeks:

‘It’s like a war zone. There were a lot of people who all wear full hazmat suits with masks and then a guy with the goggles and a shield, gloves.... You don’t actually prepare for it until you step your foot into that setting. There are some residents pretty much running the scene. There are some attendings, but nurses? There were very few nurses.’ (ICU_MD_1003)

War metaphors in the treatment of illnesses abound. Our modern philosophical separation of care from cure has left us without a non-binary word to describe the actual multifaceted handling of illness. We tend to lack language to describe an approach to disease that is not grounded in the presumptive beneficence of a certain strategy or choice; typically, a militant one. Predictably, the fear of the virus and the medical and political vernacular became reminiscent of war – cure was winning; death was the ultimate loss. Similarly, our everyday speech centres on dichotomous illness-management phrasings. We refer to people who either ‘beat’ an illness or ‘lost their battle’. After her diagnosis with breast cancer, writer and filmmaker Susan Sontag (1978; 1989) wrote about the various mythologies we develop in order to deal with illness and how the majority of metaphors we use are borrowed from military vocabulary. Such metaphors, she argued, often isolate both patients and caregivers and distort the reality of the illness experience. Author Christopher Hitchens (2012) added to this observation in his biography. Discussing his experience of oesophageal cancer, he wrote:

there's one that I find I am not saying with quite the same conviction as I once used to: In particular, I have slightly stopped issuing the announcement that 'Whatever doesn't kill me makes me stronger.'... In the brute physical world, and the one encompassed by medicine, there are all too many things that could kill you, don't kill you, and then leave you considerably weaker. (Hitchens, 2012: 253–6)

This concept was likewise illustrated in our global dialogue on the COVID-19 pandemic. Severe acute respiratory syndrome coronavirus 2 (SARS-CoV-2) became our common enemy. We needed to declare war on the virus (Craig, 2020). The rhetoric uttered by world leaders, politicians, journalists and some scientists alike was in equivalence with wartime appeals. However, declaring war on a disease may have hidden costs, such as the acceptance of risk and fatalities on the part of both civilians and soldiers – here, healthcare workers or their family members (Semino, 2021). As one nurse recounted, highlighting the toll taken when fighting illness is viewed as a war:

'These nurses were coming back to work. Meanwhile, their husbands had just died because they got them sick, or their son was upstairs in the ICU, or their family was also sick and they were having to come back to work because if they didn't, they would lose their job.' (ICU_Nurse_2004)

Healthcare workers, doctors, nurses, emergency medical technicians and support staff risked becoming infected themselves or infecting their own families. They made extraordinary sacrifices to care for patients and were expected to rush back into the battlefield that may have claimed the life of a spouse through their initial presence on that battlefield. Luc and colleagues put it succinctly, writing: 'physicians have a professional obligation to act in the best interests of patients and to do no harm, even in the face of greater than usual risks to their own safety, health, or life. This leads to a difficult question: Should we provide care without adequate protection?' (Luc et al, 2020: 359).

Our Western medical model intertwines with our speech. It is biased to providing exclusively aggressive or curative treatment when there is hope of winning and to attending to the comfort of a patient only when all options to wage war on the illness have been exhausted (Sabucedo et al, 2020). Similarly, yet understandably, the comfort of COVID-19 patients often needed to be placed behind aggressively militant strategies. Unlike with cancer, it was not just extremely difficult to determine who could be saved and who was beyond saving; even determining what was helping the patients also became fraught with uncertainty. In the words of a nurse: "This is a really bad disease that we don't have good care for, and so a lot of these people are dying because either the supportive care that we have isn't working or this system is so overwhelmed that the best that we were doing is not helping" (ICU_Nurse_2003). In the meantime, addressing the possibility of death tended to take on a secondary role:

'I think no one held their hand when they passed.... But I also think that because the families weren't able to see their loved ones, even though it was just on a FaceTime or iPad, that that was the hardest for them, and they didn't want to let go. Because a lot of them came in kind of walking in and then got super-sick.... But no one really talked to them about how critically sick a lot of these patients were.' (ICU_Nurse_2001)

In the effort to beat the enemy, many care-related necessities fell by the wayside. Whereas critical care would seem crucial, it could simply not be prioritised:

‘We didn’t have any physical therapy. We didn’t have any early mobility. We didn’t have pillows to turn people. I had one guy. Because he was on his ear, being prone, his whole face was swollen and it was cellulitis from the ear wound. I told the doctors, I’m like, “Do we want to scan it?” They’re like, “No. Whatever.” I’m just like, “Half of this guy’s face is.... This is an infection.” They were like, “It’s okay.”’ (ICU_Nurse_2002)

While aggressive measures seemed necessary, patients experiencing physical weakness also benefited from a focus on care. The role of nurses became all the more important. In the words of two MDs:

‘Everybody was also profoundly weak. We didn’t expect that ... even patients who had been intubated for just one week, there is a component of weakness to this disease that we don’t understand. And so, people couldn’t even lift their arms off the bed.... They’re so dependent on nursing care. And so, I think that that’s where maybe [the New York City medical centre] also have a leg up is just nursing care that was willing to provide the care. I can’t say enough good things about the nurses.’ (ICU_MD_1005)

‘It’s so intensive. Each patient requires so much care, so much nursing care, so much physician intention.... It’s a full-time job normally, right? So, I think they had the best that I could have had and considering that my staff was minimally, if at all, trained in ICU care, I thought that they were just phenomenal.’ (ICU_MD_1001)

This tightrope act of attentiveness seemed to be the true glue holding together the lives of patients and their chances for recovery.

The relay race of care and cure: organisation during the pandemic

With COVID-19 becoming a critical focus in hospital ICUs, nurses, doctors and other caregivers had to quickly adapt to the influx of patients. ICUs were running out of space, supplies and technical equipment. Most crucially, they faced a lack of personnel. As one physician reported:

‘Personnel was the biggest challenge, fundamentally. I mean, there weren’t enough skilled professionals. There weren’t enough skilled nurses. There weren’t enough skilled RTs [respiratory therapists], there was one RT. There were no nurse assistants. As the physicians, we were just doing everything. Everyone was doing everything. The nurses were titrating the vents. We were titrating the vents. We were turning patients, cleaning patients. Everyone was operating as everything.’ (ICU_MD_1004)

This new reality also led to the disintegration of conventional structures, while traditional hierarchies proved slow to adjust. As we saw in the previous section, the

reality of COVID-19 carried a broad range of distinctive meanings. To put it simply, we find the *disease* in its narrow biomedical terms at one end of the range. At the other end, we find the *illness* as the lived experience and the difficulties and disabilities it creates in people's lives. In between, we have the *sickness*, which could be defined as the pandemic seen on a macro, social level. The literature on the disease–illness dichotomy is vast but most notably represented by the works of Arthur Kleinman (Kleinman et al, 1978). His distinctive work has impacted the wider social and medical sciences, and influenced generations of scholars and professionals. Although we are greatly indebted to scholars who have emphasised the importance of adopting proper cultural perspectives and promoting a distinction between disease (as an objective scientific portrayal) and illness (as a subjective experience), their work may nonetheless reinforce the notion that disease, per se, is an obvious, unbiased biophysical event. As subsequent scholars noted when interpreting the disease–illness dichotomy, however, culture and context affect both concepts (see, for example, Boyd, 2000; Mol, 2002). The construction of clinical reality (the disease) is as open for social evaluation as is illness. When inscribed in a division between physicians and nurses, such a distinction can be particularly deceiving, for it implies that the former is exclusively concerned with the disease and the latter entirely with the illness. As an example of this dualism, a nurse vocalised it as follows:

‘I even had a situation once where I was following them [the physicians] to do rounds. I saw the group of three going around the rooms, talking about patients. I jumped in, and one of the physician assistants was like, “Yeah, we don’t do rounding with nurses. If you want to do rounding with us, then you should go back to school.”’ (ICU_Nurse_2004)

In our interviews, however, we saw that these clear hierarchies were commonly interrupted. Patients exhibited complex and specialised care needs. In order to achieve functional professionalism, physicians and nurses needed to work together in a much less hierarchical fashion. As one MD put it:

‘I try to make it clear: there’s no hierarchy; no one’s reporting to anyone else. On rounds, we would make sure to involve the nurses. That was a big thing. And the nurses would often be running in-between rooms. The charge nurse would round with us. And I started bringing the charge on with us every day. Because the charge would often have to put out all the fires.... They would be the ones who just did all the heavy lifting and made this stuff happen.’ (ICU_MD_1005)

Increasingly, it became clear that acute COVID-19 symptomology requires an even stronger harmonisation of biomedicine’s specialised fields and skills. Underlying cardiovascular and metabolic conditions could become major contributors to morbidity and mortality, and a heavy-handed and broader-stroked curative approach taken by an uninitiated healthcare provider could be to the detriment of patients’ health and safety. Due to capacity overload, lack of specialised medical care or poor understanding of this integrative need, nurses and doctors could often not provide the support they wanted. As one nurse recounted:

'It's like, sometimes, you get to the point where you're like, I don't want to leave at night because I don't want to come back in the morning and see what happened with less staffing or different people. The hardest day was the day that I came back in and then my patient who had a mental status had gotten tPA [a tissue plasminogen activator, a protein involved in the breakdown of blood clots], and he was bleeding out of his ears and eyes and nose, and it was horrible, and GI [gastrointestinal] bleeding.' (ICU_Nurse_2001)

Indeed, it was often not taken into account that caregivers must have a high level of competence, as is the case, for example, with specialised nurses with extensive knowledge of ventilation management. Such knowledge cannot be conveyed in short training courses, and the use of inexperienced nursing and medical staff carries the risk of endangering patients. Yet, this crucial aspect of maintaining life in the ICU was mostly absent during COVID-19 ICU stays, as the following forceful example illustrates:

'So, basically, this lady has right heart failure and pulmonary hypertension, and she needs to be intubated.... She had been in the hospital with a wound, a non-healing pressure ulcer, and had gotten COVID iatrogenically and then had just decompensated over time.... It was time for her to be intubated. They said that she had [a] known RV strain [a right ventricular dysfunction where the heart muscle of the right ventricle is deformed] and we had a bed open. So, I said, "Just come to the unit. You can't intubate these people with much sedation because they just crash when you induce them." It's just a very known basic thing. And they're like, "She won't make it. We'll intubate on the floor." I was like, "Is she on the monitor?" "No." And they had this roving anaesthesia team.... So, they're like, "We're just going to do it here and bring her." As I hung up and was calling the house captain to try to get them to run over there and stop it, you hear the red code, you know what it is, and then she wheels in and it just felt like mismanagement and, again, I wasn't there, so you don't want to throw them under the bus. Then, she gets a dirty fem [femoral, the large vein in the groin that passes with the femoral artery under the inguinal ligament to enter the abdomen] line from her code. She gets a couple rounds of CPR [cardiopulmonary resuscitation], and then you look in the note and they pushed, the meds that they pushed were just wildly, wildly too much for somebody with that kind of heart, which is a basic thing to know as an ICU provider.' (ICU_Nurse_2003)

As alluded to in the previous historical section, the emergence of a care-cure dichotomy has also led to hierarchical organisational structures. 'Consistent with the nature of most dichotomies', write [Treiber and Jones \(2015: 152\)](#), 'where one part dominates, medicine has emerged as the more valued and prestigious half of the dichotomy'. Nursing, in turn, primarily adhered to the science of caring. Yet, the dichotomy also began causing a shift in values within the nursing system itself, where nurses and nursing students have been socialised in preferring a cure approach ([Stevens and Crouch, 1995](#); [McKenzie and Brown, 2014](#); [Haeusermann, 2018](#)). Caring for COVID-19 patients, then, could be particularly frustrating. As a nurse described:

‘There was no progress in the patients. There was no one patient that I had actually gotten anything done on, in the sense of: “We removed their NG tube” [a nasogastric tube that carries food and medicine to the stomach through the nose] or even put one in; or, “Look, their labs got better”; or “The CRT [cardiac resynchronisation therapy] machine took this much volume off.” There was no goal that was completed.’ (ICU_Nurse_2004)

At the same time, the absence of curative measures imposed financial constraints. The hierarchy of care and cure activities is reflected in the general economic impetus to place emphasis on curative services at the expense of care provisions. With hospitals needing to postpone more lucrative operations for months to keep their capacities free for COVID-19 patients, the financial dependence of hospitals on elective surgeries was revealed. Indeed, the cessation of curative, elective surgeries began to jeopardise the financial solvency of hospitals (Anoushiravani et al, 2020). As a result, the lure for hospitals of bolstering their bottom line and improving mortality statistics could lead to their abandoning patients when services were needed the most. In the words of an MD:

‘If they shut down all elective stuff like that, they’re not going to have any income to support the hospital. I understand that’s a real problem and a real pressure, that the CEOs [chief executive officers] and those type of people will have to deal with. They’re not heartless because they have to attend to that.... But from my standpoint, being like, “I flew across the country to work in your neurology ward that’s now an ICU, where we have two patients in a room where you’re intended not to be able to see inside, and there’s supposed to be a curtain behind them, and one of them is prone and dying in the back bed, and the other one we’re hoping to extubate today.” The idea that they would clear out one of the ICUs and reinvalidate it for elective surgery just galled me.’ (ICU_MD_1001)

In sum, various procedures that were part of a curative focus in the ‘before’ times became transformed into caring activities during COVID-19. This was due to a confluence of factors: clinicians did not know how to cure the disease (they got better over time at providing support that would allow the body to heal, for example, pronation, steroids, delaying ventilation and so on); there was a scarcity of trained professionals; and, time and again, activities turned to caring for patients who were dying.

Integrating palliative care into Covid-19 treatments

Whereas aggressive and novice curative approaches could be warranted – indeed, even imperative – for some patients, they could equally yield more perilous outcomes for others. Often absent was a dialogue on how to proceed when curative or other aggressive treatment approaches made little sense. As a result, palliative care may have been overlooked. In the words of a nurse: “There was no palliative care. There was no comfort care. None of that existed.... I wish I would have seen more palliative care, but we did hold their hand and we did bring what we could in that moment” (ICU_Nurse_2004). A medical doctor, in turn, phrased it as follows:

‘The second week, there were more cases of patients where it was very clear they were dying. Actually, nobody died the first week. Several people did die the second week. I felt like I was the only one addressing the bigger question about, “What are we doing here?”, and “Do we want to have a goals-of-care conversation on these people who are actively dying? Why haven’t we done that?”’ (ICU_MD_3001)

Providing comfort and planning throughout the course of an illness, regardless of expected outcome or phase of illness, can benefit patients (Strand et al, 2013). Palliative care aims to provide pain and symptom relief, regardless of the disease stage or prognosis, and can be provided in tandem with curative treatment. Its goal lies in improving patients’ quality of life, assisting them in understanding their treatment options and better preparing patients and families for any course their situation may take. Indeed, even in ICU treatment, palliative care is associated with better curative outcomes, as well as with better end-of-life quality and planning for those for whom cure has failed (Mercadante et al, 2018). Similarly, early integration of palliative care in oncological diseases with less predictable trajectories can help ensure that patients receive proper end-of-life care and that patients’ quality of life is a priority; it can also help extend patient survival (Verhoef et al, 2019; Temel et al, 2010). However, the benefits of palliative care can be overlooked when approached through the lens of a dichotomy. A conflation between palliative and hospice care, for instance, was found to lead to underutilisation of palliative care among late-stage heart failure patients due to patients’ typical experience of palliative care associated with late-stage disease management (Metzger et al, 2013). These findings suggest that greater flexibility in treatment plan options and the integration of palliative care in early disease treatment stages can lead to enhanced patient understanding of the benefits of palliative care. They equally reveal that our current options for disease management are interpreted dichotomously by the very population we intend to serve. As current COVID-19 treatment protocols rely on ICU patient maintenance, it would seem all the more important to integrate palliative care into treatment protocols, as well as incorporate conversations about end-of-life scenarios and treatment preferences. One nurse detailed how there were no conversations conducted with family members about the precise likelihood of death; rather, the focus lay solely on continuing to treat:

‘There was no palliative care there at all. There was no talk about it. The one patient I had, he was 74. He has chronic kidney disease to begin with, diabetes, hypertension, lots of co-morbidities, maximum settings, on three pressors. They would keep calling the family. They would call the family at 2:00 in the morning and be like, “I don’t think he’s going to make it”, but they wouldn’t say, “He’s dying. We’re sitting here pushing meds to keep him alive.” They’d go, “I don’t think he’s going to make it through the night” and then the family would be like, “Okay, but we were very hopeful. We want to keep trying.” They wouldn’t say, “He’s actively dying right now.”’ (ICU_Nurse_2002)

Many elderly people and those with chronic or serious illnesses no longer want all life-prolonging measures performed. When patients lack the capacity to make such judgments, advance directives are a way for them to communicate their wishes,

yet fewer than one third of US residents have completed an advance directive to guide care when seriously ill (Yadav et al, 2017). In a crisis situation, such as with COVID-19, the sudden onset of symptoms can lead to poor documentation of treatment requests. Yet, in the case of a severe course of COVID-19, the role of life-prolonging measures only becomes clear after several days of artificial ventilation. If someone does not want to be intubated a priori and possibly no longer hospitalised, it is helpful to discuss this explicitly with relatives. In COVID-19 treatment, there may be a short window to have discussions with patients or with family members. By not actively discussing death and end-of-life planning, the family may be robbed of an opportunity to come to peace with the outcome, and the patient may endure unnecessary and potentially uncomfortable treatments as they approach death (Hick and Biddinger, 2020). An MD explained it as follows:

‘I also felt like we had an obligation to try to at least address basic issues of comfort and dignity that were not getting addressed. We ended up shocking this poor woman who ended up dying four times.... Her brother was actually admitted to the hospital. They came at the same time. He was her only next of kin. They were each other’s only next of kin. They didn’t have anyone else. He kept saying, “No”, when the resident or intern would call and say, “We’re out of options. We should talk about comfort care.” Finally, the morning that she died, after she’d been shocked three times, I said, “Let’s go see him”, because he was in the hospital. I said, “We have an advantage actually in a weird way that he’s here. Let’s go sit down and talk to him.” We were able to convince him that this was really not in anybody’s best interests to keep shocking her. She ended up dying.’ (ICU_MD_3001)

Part of the reason that palliative care was rarely discussed appears to be a lack of connection between healthcare professionals and families. The nature of COVID-19 and the ensuing protocols made it difficult for providers to establish rapport with families (Kumaraiah et al, 2020) – a necessary step for building trust that is so often a cornerstone of successful implementation of palliative care. An MD phrased her experience:

‘The whole experience of addressing prognosis and goals of care and end-of-life issues is just horrible when the only way that you can talk to somebody is once a day in a 10- to 15-minute conversation. You never get to see that person. They never get to see their family member, except if you can kind of MacGyver some way to FaceTime with them from the room while you’re wearing your PPE [personal protective equipment] in front of the bed, so that they can see their family member on a ventilator. Right?... It’s a situation that lends itself extremely poorly to evaluating the overall course.’ (ICU_MD_1001)

Additionally, the uncertainty of COVID-19 appears to have been a significant barrier to palliative care discussions. Patients often experienced acute and sudden onset of symptoms. It was sometimes unclear who would die and who would likely recover – COVID-19 remains a disease with a lot of unknowns in the trajectory, complicating and stymying decision-making processes. As one MD described:

‘I do think people are being aggressive, and I think it’s probably the right... Maybe I’ll just say for diseases where you understand what’s happening, you understand natural history, you understand what’s ... that I think I am comfortable being relatively favouring shifting the attention to comfort and dignity. I think I’m less comfortable here because we just don’t know who’s going to get better. I don’t think we even have any way of predicting who’s going to get better and who’s not going to get better. I think it probably does make sense to be cautious about being overly aggressive about end-of-life care in this disease that we don’t even understand.’ (ICU_MD_3001)

Finally, it may be difficult to integrate palliative care with the necessary aggressive approach to handling a new and unknown disease. The term ‘palliative care’ is comprised of the word ‘care’ and falls into the dichotomy, thus insinuating trade-offs in choices. As the ultimate desire is to cure patients, caring for COVID-19 can seem to run counter to the efforts undertaken by medical providers. In the words of the same MD:

‘I will say my own personal opinion about how aggressive I would want to be in this disease evolved a lot over the two weeks that I was there. I think when I first got there and I saw how horrible it was and saw what was happening to people ... I would joke around and say, “Give me 24 hours and a vent, and then I’m done.” I think I came to realise that that was naive. This is an unusual situation, and we don’t have a playbook. There’s no playbook for this disease. It’s a brand-new disease. I think whereas with end-of-life care around cancer or heart failure or other things, I understand when someone is dying of one of those diseases.... I think I probably would have a very different approach dealing with myself or a close family member in giving it more of a chance in a younger, healthier person, not the people.... I don’t think we did anything wrong with the two people who ended up dying. I think that was handled incredibly appropriately. I think maybe some of the hesitation I had around how aggressive to be in just any case of this disease, I think that changed.’ (ICU_MD_3001)

Choices surrounding palliative care – and the conversations they entail – are a debated topic in the US medical system (Patel and Kruczynski, 2015; Buss et al, 2017; Whitelaw and Clark, 2019). Palliative care discussions, which traditionally take place behind closed doors, have been illuminated by the contexts that arose during the pandemic. The pandemic highlighted the necessity of having those conversations within the requisite timeliness and the consequences for patients, families and medical providers when the conversations are neglected (Radbruch et al, 2020). Yet, it also brought to light tensions between palliation as a type of way to address disease to improve outcomes, palliative care as comfort care and end-of-life care that is more consistent with patient/family values.

Discussion and conclusion

Whereas we discussed some inconsistencies and limits of today’s medical models, our purpose in this article is not to make claims about ‘right’ or ‘better’ care. If we were

to do this, we would fall prey to the very issue we seek to address. Rather than a call for new models, this article should serve as a vehicle for debating the dangers of providing dichotomous interpretations of illnesses. Caring for COVID-19 is uncertain terrain, and the events we highlight in the interviews are born from unprecedented circumstances. While we aim to bring attention to strategies and outcomes, it is clear overall that much dedication, zeal and commitment went into COVID-19 treatment. Beyond diagnoses lie individual people – medical providers, patients, caregivers and family members – flawed and confounded by the truly extraordinary events. Providers operated under threat to their families' and their own health, and were forced to adapt with little systemic support. Some restrictions were due to the nature of the crisis, while others originated from developments in the medical establishment and beyond that had been long in the making (Lupton and Willis, 2020).

In our modern medical world, as we seek greater definition of disease aetiology and symptomology in order to target diseases as specifically and relevantly as possible, we typically aim to focus on the normative course of a disease, instead of on individually varied trajectories. The drive for specialisation that arose out of the 19th century further embedded the value of curative therapies, occasionally at the cost of holistic care. At the height of the pandemic, some medical professionals who were used to relying on predictable, quantifiable outcomes may have struggled to transition to a primarily care-based approach involving multi-system issues over an indeterminate length of time. It demanded a readjustment to a reality where caring is the best we can do. As it transpired, we were not primarily combatting a virus in a heroic fight. On the contrary, our best-developed treatment strategy was to retreat from it and wait it out, while supporting the patients. The language of war and the logic of military structures were not compatible with our complex human bodies and pluralistic social structures.

The conceptual loads that disease and illness, and, relatedly, cure and care, each bear trigger sociobiological and cultural superiority and inferiority as underlying social judgements to individual disease-management choices (Baumann et al, 1998; Treiber and Jones, 2015). One may think that the divergence of care and cure from their joint root is warranted, as some disease states offer the possibility of a cure while some exclusively require care. However, as COVID-19 highlights, such a distinction can ignore the physical, social and psychological complexities of illness and its handling. In today's era of chronic illnesses and multi-morbidities, dissecting disease along clean lines of definition or body parts risks missing the whole of the experience and the opportunity to provide the best care or cure to patients.

Moreover, with respect to most modern diseases, the dichotomous approach of sorting illness into curable and incurable brackets – in addition to health costs – can burden both patients and caregivers with social, personal and psychological costs. If choice of action is dichotomous, it is possible for moral standards to emerge in regard to choices made. Choosing non-curative care may be considered giving up; choosing aggressive treatment may be seen as futile heroics. Thus, patients can potentially be stigmatised for their choices in handling their illness, in addition to any stigma they may bear in contracting COVID-19. If each choice carries stigma, individuals may feel pressured into choosing one option over the other, as opposed to combining and harmonising an individualised and optimal course of action. Dichotomy can lead to believing that there is one way to 'do' the disease. In short, perpetuating a dichotomy between care and cure may render a disservice to both.

If our aim is to increase patients' quality of recovery and life, it may be time we remembered the shared heritage of care and cure, for each contains, reflects and refracts elements of the other. As their centuries-long evolution demonstrates, the two concepts, along with their meanings and constructions, have been, and continue to be, constantly renegotiated and rearticulated. What could appear as a mere philosophical or epistemological debate can produce very real and tangible consequences for patients, caregivers, health systems and societies.

Notes

¹ Given its historically broad interpretation, defining care is a non-trivial task. Joan Tronto and Bernice Fisher have offered an influential definition that classifies care as all activities that help to 'maintain, continue and repair "our" world so that we can live in it as well as possible' (Tronto, 1993: 40). Elsewhere, we introduced a definition of care in healthcare as follows: 'Care in healthcare is a set of relational actions that take place in an institutional context and aim to maintain, improve or restore well-being' (Krause and Boldt, 2018: 3).

² In accordance with our approved protocol, in this manuscript we refer to participants using coded identifiers to maintain anonymity and confidentiality.

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Conflict of interest

The authors declare that there is no conflict of interest.

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