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During the COVID-19 pandemic, health care routines have shifted dramatically. Ill patients are dying without their loved ones and few patients are allowed advocates in hospitals or doctor's offices; COVID patients are allowed none. Less dramatic but still significant: primary care has been moved online and elective procedures postponed indefinitely. The crisis has brought about a new turn in the historically contingent understanding of patient care and prompted new questions about what constitutes comprehensive health care. Do the necessary lack of or profound change in patient care brought about by COVID-19 constitute a secondary public health crisis? Or will we find we need less than we thought? Does the ideal of care include emotional comfort and access to one's loved ones, or is physical wellness primary? Scholars, physicians, and activists have been asking these questions for a long time, often trying to balance individual and collective needs.

Physician and researcher Sidney Farber developed the term "total care," in the 1950s while working with pediatric cancer patients; the term, along with its successor "total therapy," would be well-known throughout the United States by the next decade. After noticing increasing survival times among his patients, Farber and his fellow researchers at Harvard Medical School developed policies that would "subordinate clinical investigation to patient welfare"; they would no longer conduct trials on patients if it interfered with their "survival or comfort." While Farber's focus shifted to the individual patient, he also recognized patients as part of a "whole family," with psychosocial and economic needs alongside the patient's physical needs (Keating 81-82).

Meanwhile, outside hospitals and labs, activists and healthcare experts pushed for a more comprehensive — and shared — understanding of care through their own knowledge and experience. Key influences include the American Civil Rights Movement, and the work of educator Paulo Friere and his work on educational empowerment, which has been since been adapted by some medical researchers and physicians into a medical context as a necessary part of patient care (Pulvirenti). The idea of "empowerment" evolved again with the Alma Alta Conference on Primary Health Care in 1978. The goal of the conference was to promote and implement "Health for All" throughout the world through the means of primary health care. The conference Declaration "reaffirm[ed] that health, which is a state of complete physical, mental, and social well-being, and not merely the absence of disease or infirmity, is a fundamental human right..." (World Health Organization).

In 2001, the Institute of Medicine proposed "patient-centered care" (PCC) as one of its six goals for improving health care. They defined PCC as "providing care that is respectful of and representative

to individual patient preferences, needs, and values and ensuring that patient values guide all clinical decisions” (Kupfer 139). Some doctors and scholars downplay this definition, arguing that the goal of PCC is to reconcile “patient satisfaction” with their medical needs. (Kupfer 139, Epstein).

While consumer dynamics undoubtedly play a role and all care is constrained by finances, to dismiss patient needs as mere “satisfaction” downplays their significance (Brett 150). PCC is more than just “giving patients what they want, when they want it”; it represents a collaborative model. Additionally, it recognizes that physicians and medical structures have power and requires them to “appropriately share power even when that sharing feels uncomfortable” (Epstein).

For health care providers and patients alike, these goals have always been difficult to achieve and complicated to define. Physicians worry that “allowing patients’ demands for unnecessary interventions to trump careful clinical reasoning results in a nondeliberative, rote practice style that undermines clinical excellence” (Kupfer 140). Moreover, the momentum and capacity to achieve ethical and substantive care has fluctuated with every public-health crisis and historical period. Among other terms, at various moments, “the patient” has been constructed as a consumer, a self-manager, and a survivor, all of which carry varied meanings and expectations. Today, physicians continue to work toward critical analysis of patient care, while health-advocacy organizations and university graduate programs work to approximate the most ethical functioning of the term (Kupfer 140).

The COVID-19 pandemic has called into question these tentative understandings of patient care and public health: What counts as clinical excellence when health officials lack the tools they need to do their jobs? Where is the room for patient preference in an overwhelmed hospital? What kind of empowerment is possible for a COVID patient with no health insurance? How do we take the best care of the most people when there won’t be time for critical analysis until much later? There seems to be no room for even a basis of total care.

Here, recalling Firere’s use of empowerment is grounding. While “empower” is a perennially ill-defined term and framing care as empowering can “presuppose a disempowered individual” (Pulvirenti), empowerment health care has a longstanding working definition that “involves people in group efforts to identify their problems, to critically assess social and historical roots of problems, to envision a healthier society, and to develop strategies to overcome obstacles in achieving their goals” (Wallerstein 380). The call for empowerment in the Alma Alta Charter is also instructive when it states: “The people have a right and duty to participate individually and collectively in the planning and implementation of their health care” (World Health Organization).

These models show where empowerment— an often depoliticized term— intersects with a “whole systems” model for patient care, which demands consideration of the structural and political forces that impact individual and collective health (Greenhalg). Moreover, the whole-systems model proposes a focus on “person”— rather than patient— centered care, which seeks to include those trying to achieve wellness—and avoid illness—outside of formal, official care settings.

Observing our moment's stunning lack of care resources on a structural, yet person-centered level allows us to think about how people who have died at home during the pandemic should be categorized; while they were never patients, they are victims of the virus. It also instructs us in how to conceptualize those of us who have forced to become "self-managers" who are asked to make the best of telehealth—taking our own blood pressure and temperature and foregoing primary, or even essential, care to avoid becoming vectors for the virus (Pulvirenti). In many ways, the pandemic has pushed the public to treat all people-patients as a collective, part of the whole who must sacrifice to avoid greater suffering. But to what degree? Many people might be able and willing to socially distance, but what about dying or giving birth alone? The circumstances of the present moment preclude patient satisfaction and there seems to be little space for the shared decision making many physicians and researchers call for (Kupfer 139).

These impasses ask us to reconsider the question of who qualifies for patient care: the sickest among us? Those most likely to get well? Does the future of public health outweigh the wellbeing of living individuals? We must also reconsider the standard of an "improved health outcome" (Kupfer 140; Greenhalg). How do we rationalize the tension between the goal for fewer people to die with that of a good death for those who die? Any answers will take time to emerge; assessing patient care "inherently longitudinal" (Lee 1812). Yet, while the traditional benchmark for observing the effects of a care trajectory is an individual patient's lifetime, the pandemic changes the timeline: the long-term effects of this moment will take years to determine and will only be complete when including the changes in organizing and political movements that will emerge during and after the pandemic in our analysis.

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