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Responding to the crisis of care

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Healthcare is in crisis across most of the globe, and perhaps particularly in our two countries of the United States and the United Kingdom, both of which appear more disunited than ever by the greed and carelessness that drive socioeconomic and political polarisation, and the systematic degradation of our planet.

There are two possible responses to this crisis.

The first assumes that this is simply a crisis of organisation, efficiency, information, technology, and scale. It sees people as insufficiently studied biological machines, as sparsely detailed clouds of data, as inadequately monitored and regulated physiologies. The increasingly ruthless pipedream is that, if only the healthcare industry could access and use everyone's biomedical and socioeconomic data, then their needs could be predicted, and a healthy future would be assured for all. Industry is already reaching out through the sale of technological devices on wrists and in pockets, in homes and at work, encouraging their consumers to act, cajole, or force action or recruit others to prevent disease and suffering; all the while forgetting that, in the end, everyone must die. The biomedical science and technology discovery machine produces tests and treatments to be delivered by chatbots to isolated consumers without the frictions and costs of having to deal with other people. They are set to operate in healthcare systems at scales of speed and reach that are only possible when we abandon the idea that care is only possible between people. This response fuels the ever greater involvement of large retail and data corporations in healthcare, and drives the increasing consumption of pharmaceuticals and medical technology, all of which wilfully ignores the consequences for the planet.

The second response assumes this is a crisis of care in and of itself. Care happens in the space between people, in an unhurried encounter. Only humans in interaction can care. It is in this interaction in which one notices a problem in the other and seeks to respond to the other's predicament to improve their situation. In healthcare, this noticing goes beyond the biological to appreciate the biographical, and, fully aware that bodies are not machines and that emotions—both positive and negative—exert a powerful influence on every aspect of health. It goes beyond what makes living possible to consider what makes living meaningful. Care is not just the adherence to evidence-based guidelines to improve population-level metrics. The work of care discovers or invents ways forward. The effort of care fosters hope that the situation could be better in the future. It results in a way forward co-created with the intention of comforting always, while spanning from complex surgery to keeping company with the dying, from fixing to alleviating. This response is human, so it is fraught with friction, bathed in radical uncertainty, yet resilient to recurrent disappointment thanks to the close personal relationships within which care happens.

Over this summer both of us read Rebecca Solnit's latest book, *Orwell's Roses*,[1] which she was inspired to write when she discovered that George Orwell had not only written the bleakest and most powerful portrayals of the totalitarian regimes of the twentieth century,[2] but had also planted rose bushes, costing him sixpence each from Woolworths. This apparent contradiction between the bleak worldview and the hopeful act of gardening, reminded Solnit of the political slogan "Bread and Roses" which seems to have emerged in the US around 1910 and was used by women campaigning for votes for women and for workers' rights. Describing the power of the slogan, Solnit wrote:

"Bread fed the body, roses fed something subtler: not just hearts, but imaginations, psyches, senses, identities. It was a pretty slogan but a fierce argument that more than survival and bodily well-being were needed and were being demanded as a right. It was equally an argument against the idea that everything that human beings need can be reduced to quantifiable, tangible goods and conditions. Roses in these declarations stood for the way that human beings are complex, desires are irreducible, that what sustains us is often subtle and elusive."

"Bread and roses" are what the humans involved in care—the patient and the clinician—want from healthcare. Bread is sustenance and therefore life; roses are courage and hope, curiosity and joy, and all that makes a life worth living. Bread is biology; roses are biography. Bread is transactional and technocratic; roses are relational. Bread is science; roses are care, kindness and love.

"Bread and roses" can also describe how healthcare can support care. With apologies to those who bake their own loaves, the parallel here is with the industrial production of bread, so that bread represents the bureaucratic processes that make healthcare efficient and safe, preventing waste and error through standardisation, regulation, and training. Baking bread is like the technologies and innovations that make unhurried conversations and continuity of care possible and feasible, that reduce diagnostic errors, and detect and correct harms early and reliably. Attending to the bread makes sure healthcare retains the potential to attend to the object of care, to the bodies and minds, the fears and feelings of individual patients, and to create the conditions for careful and kind care to emerge.

Roses represent what makes life worth living, all that is good in human relationships, and the stories we use to make sense of our desperate situations and of

what is possible with treatment. Roses are what gives us comfort in the face of failure, pain, decay, and death, that is, in the face of living. Attending to roses brings the subject of care into sharp relief so that the scars of injustice, racism, inequity, and violence can be made visible alongside the scars of disease. Roses, like careful and kind care,[3] speak of hope—our work of planting and creating conditions of light, soil, and water makes it possible that a flower will appear in the future. Just like roses, care cannot be summoned or coaxed, but must emerge from the right conditions.

Post-pandemic industrialised healthcare is mostly a hard slog driven by an externally-imposed obsession with numbers. This is causing widespread moral injury by coercing professionals to prioritise ever more interventions that they know to be futile while banishing any trace of a rose for patients, or for those who try to care for them. The moral scaffolding of industrialised healthcare is increasingly at odds with the ethical and moral imperatives of the actual work of caring for the sick. The result can only be cognitive dissonance and moral injury, disappointment and anger, dissolution and exit. As Rebecca Solnit puts it,[1] the ethics of caring are maligned as,

"...trivial, irrelevant, indulgent, pointless, distracted, or any of those other pejoratives with which the quantifiable beats down the unquantifiable."

We have forgotten the limits of industry and technology before. We have let some forms of material progress and growth take precedence over dignity, justice, solidarity, and sustainability. An excessive attention to bread has left us with the impression that caring is a finite resource, its scarcity demanding it be administered, regulated, and rationed. We are living with the consequences of Joni Mitchell's paved paradises,[4] realising how healthcare feels when care is gone, when care givers not just burn out but show up to care for patients even though they themselves are depleted, when patients seek care, but the business plan and the algorithm prescribe cruel indifference.

How to respond to this crisis of care?

Here, Orwell himself holds the clue. The discovery that Orwell had planted those roses led Solnit to reassess his novel *1984*. Within all the greyness and cruelty and oppression, there is this great truth:

"What mattered were individual relationships, and that a completely helpless gesture, an embrace, a tear, a word spoken to a dying man, could have value in itself."[2]

All the joy, all the roses of health, even in these dire times, exist within relationships, between patients and professionals, and between healthcare colleagues; and in the sure knowledge that all these helpless gestures have value in themselves.

It turns out that the subversive, almost revolutionary thing to do within contemporary healthcare is to build, quietly and unobtrusively, these crucial relationships. We now know that continuity of care, within a unique dyad of patient and doctor, delays disease and prolongs lives[5] and thereby supplies bread, but it does so by simultaneously giving us the roses of joy, trust, curiosity, care, kindness, and solidarity. A life worth living tends to last longer.

In fact, care, like love, is abundant and self-sustaining, a potential of everyone. Trained and celebrated, caring is a demanding human capability that swells with the satisfaction of having opted to run towards the pain, that replenishes with the smile and the gratitude with which we evaluate our effectiveness, that regenerates when the care, and love, returns to care givers when they, invariably, must become care receivers. Care, like roses, gives meaning to living. We must cultivate care.

In fighting our way out of this healthcare crisis, in working for careful and kind care for all, we must follow the suffragettes and demand "bread and roses."

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3 Montori V. Why We Revolt: a patient revolution for careful and kind care: The Patient Revolution, Inc. 2017.
4 Mitchell J. Big Yellow Taxi. Ladies of the Canyon: Reprise Records, 1970.
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