Achieving care: promoting alternatives to industrial healthcare

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Summary

We march toward industrial healthcare. With different intensities and speeds depending on the nature of each healthcare system, most countries exhibit features of industrialisation. Perhaps this is the case because industrial healthcare may represent the final common pathway for any system that becomes underfunded as a result of austerity or profit extraction. Industrial healthcare is cruel to those at the frontline. It displaces the language of care, which in turn affects how we think and decide. It is time to reframe the conversation, change the language and draw from the traditions of the caring sciences. By focusing on care, developing models for caring and learning based on the actions of people rather than on data, and developing data based on the problems of care rather than on the advancement of decontextualised knowledge, we can advance toward careful and kind care for all.

Keywords: patient-centred care, clinical care research, medicine

Our care problem

Medicine, to be useful, must develop a response to the problematic human situation of patients, and the patient has to be at the centre of this response. This requires that clinicians – anyone with the privilege of the bedside – correctly understand the nature of the situation and find an approach to care that makes that situation better, or at least more tolerable. Increasingly, the problems patients put before clinicians are complex [1]. They involve the co-existence and interaction of chronic conditions emerging and disrupting complicated lives. The care plans that are formed in response to these problems must be enacted within already busy routines, woven through schedules interrupted by improvisation and unpredictable demands from family, work and community. Medicine must therefore see the patient's biology and biography, their problems in context, their situation in high definition. Some elements of the situation are detectable with the senses and laboratory tests, whereas others only exist in or can be appreciated through the patient's perspective.

Thus, to respond well clinicians must engage with patients with compassion and technical competence, and patients must participate in care to the greatest extent possible. This partnership should arise from continuity of care, mutual trust from unhurried conversations, diagnosis, deliberation, and decision from their dance [2]. The care plan that emerges should make sense medically – likely to be effective and safe – but also emotionally and practically, as the plan of care will have to fit the patient's daily life. The plan should avoid making unreasonable demands on the patient's resources and be respectful of their time, energy and attention [3]. Care must be both careful and kind.

Unfortunately, in many health systems, patients cannot enjoy careful and kind care. They instead enter a vortex, a transactional visit with an overclocked clinician, with the contact too brief and the tempo too fast for dancing, and the patient's situation too ill defined to elicit compassion, which fails to result in a correct diagnosis and a sensible response. Instead, this so-called industrial healthcare responds to patients who have poorly understood problems with standardised care for *patients like this* – short-sighted and aimed at improving measurable markers of disease – rather than care particularised for *this patient*. This generic care is either insufficient or the opposite, the latter resulting in over-testing, referrals to other clinicians, fractured care and dangerous polypharmacy [4]. Patients end up overwhelmed by the burden of illness inadequately addressed, or by the burden of care that is abundant but ineffective.

Care plans fail to respond to a situation that clinicians cannot appreciate well because of chronic underinvestment in time and the relentless pursuit of efficiency without efficacy, of standardisation without personalisation, and of documentation of care without care. Industrial healthcare demoralises clinicians, erodes their professionalism and disconnects them from the purpose of practicing medicine [5]. By forgoing the emotional fuel of offering compassionate care, they develop emotional exhaustion, depersonalisation and a sense of personal ineffectiveness, symptoms of burnout that further inhibit the possibility of care [6]. Take the clinician who allows periods of silence, either in the consultation to deepen the connection with the patient and elicit the patient's story, or between consultations for the clinician to self-centre and be more present with the next patient. These precious moments of silence, under the lens of efficiency, are wasteful. Clinician dissatisfaction is an early warning sign of a healthcare system creating bar-

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riers to high-quality practice [7]; burnout and withdrawal from the practice of medicine are its lagging indicators. Industrial healthcare is thus cruel to those who care and those who seek care.

Promoting a language of care

Language influences the way we think and act [8]. A vocabulary of production – providers, consumers, efficiency, delivery – has trickled down from business and engineering back offices to the point of care. These terms are often used interchangeably within the lexicon of clinical care and the expressions that have arisen from the traditions of medicine. Consider the term *consumer*, increasingly used in recent decades to denote *patients* [9, 10]. Some argue that the term "patient" summons an image of a passive individual awaiting treatment [11], closer to the word's original meaning of "the one who suffers"; in contrast, the "consumer" is the sole arbiter of his or her needs [12]. This intrusion of industrial language into everyday clinical care creates distance from the core mission of medicine, and the result is use of language foreign to patients and clinicians in the frontline of care. For example, patients as consumers are expected to take responsibility for "shopping" for the right care and demanding that healthcare satisfies their wants. Those fluent in the language of industrial healthcare – policymakers, health insurance companies, and healthcare administrators and leaders – have an advantage as native speakers of this language, whereas clinicians and patients must become bilingual to engage with them, while slowly losing fluency in the mother tongue of care.

When patients are considered consumers of healthcare and clinicians as providers or suppliers of the product [13], "healthcare" is reduced to a commodity [9], and the sacred space for curing, caring and alleviating becomes a service experience [14]. Those most likely to be affected by this shift are those who fail to improve on their own or after a standard healthcare response: the underserved, the multimorbid, the disadvantaged, the institutionalised, the marginalised and those living with chronic conditions for which there is no medical explanation [15]. Engineering processes can make healthcare safer. Business processes ensure the best stewardship of precious resources. As such, these processes are essential. It is their introduction at the point of care – via incentive pay for processes or outcomes, standardised checklists to improve the efficiency of the clinical encounter – that contributes to the industrialisation of healthcare.

Promoting people-centred frameworks

As healthcare generates large volumes of data in the course of caring, there has been growing interest in harnessing these data to improve the performance of healthcare [16]. The so-called learning healthcare system hinges on use of these data to optimise healthcare performance for populations [17]. In contrast, the Care and Learn Model places people, those caring and those who receive care, at the centre of the system [18]. During care, carers react to the problematic human situation of patients by assessing, by using the best evidence available to fashion a response and by organising information, technology, policies (e.g., guidelines, protocols) and people to implement that response. Learning takes place as people evaluate the response, gen-

erate evidence about it and adapt it to achieve patient goals. To work, the model hinges on the participation of people involved in caring and receiving care; it recognises and integrates the social context in which people live, and face and solve health problems, and with which healthcare must interact to improve health.

The Care and Learn Model shows healthcare responding to problematic situations and learning from its experience. By closely integrating caring and learning, this framework grounds the design, conduct and evaluation of clinical care research, as well as the implementation of innovations and quality improvement programmes, on the problems of caring for people.

Promoting research addressing care gaps

An extension of industrial healthcare, the biomedical research enterprise, appears to pursue the next research question identified from emerging knowledge gaps. Common motivations to close these gaps are personal promotion, securing research funds and advancing a product to market. The product of this work is evidence that may or may not be useful in caring for a person, which in turn calls for efforts to translate evidence into practice. Such "push" approaches differ from the "pull" approach of the Care and Learn Model, in which addressing the problematic situation of the patient requires a carer to draw from a number of sources, including the evidence base, to formulate a response. It is in the process of care that we learn of gaps in our knowledge of how to respond that call for research, yet funds to bridge these gaps are scarce, resulting in underfunding of research into the care of people with multimorbidity, for example, the most common chronic condition in the developed world [19]; even when funded, the research is usually decontextualised of its social and economic manifestations [20]. This makes it challenging to care, for example, for people with chronic conditions when a key component of their suffering is financial, either as income foregone because of illness or expenditures to cover the costs of care.

Focusing research on responding to care gaps should readily advance the care of patients and translate swiftly into usual care. The place where these questions are found is at the frontline of medicine. This calls for researchers to partner with patients and clinicians, and to embed their work in the clinical encounter, where we learn about patients' struggles and the problems with care that caring clinicians work to solve. Often, the problem is not a lack of evidence or information, but a situation that is difficult or overwhelming. Still, evidence has a fundamental role here, to support treatment decisions by uncovering the relative merits of available options not only in terms of risks and benefits but also in terms of the necessary effects these options will have on most people who use them. The evidence about the effect of care on practical issues, such as how a treatment affects travel, recreation, diet, work, or relationships, remains woefully underdeveloped, demonstrating another limitation of research based on knowledge gaps, which keeps a blind spot on care [21, 22].

Promoting careful and kind care

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