THE PATIENT REVOLUTION

RESOURCES

Foundations of Our Movement

The Words We Use

Industrial healthcare is humanly unsustainable

In industrial (or industrialized) healthcare, patients access healthcare and are processed. Throughput and efficiency are closely optimized. It does not matter which patient is seen by which clinician, each interchangeable by someone with similar characteristics.

This is not to say that kindness never happens in industrial healthcare. Many people can speak to a visit or interaction that left them feeling deeply cared for. But you often find that these moments are the result of individual heroics: a doctor who makes a point not to interrupt even if the visit goes long, a scheduler who finds a way to squeeze an appointment in recognizing the urgency of the situation. The environment isn't set up to produce this kind of care. Those moments are the exception, not the rule.

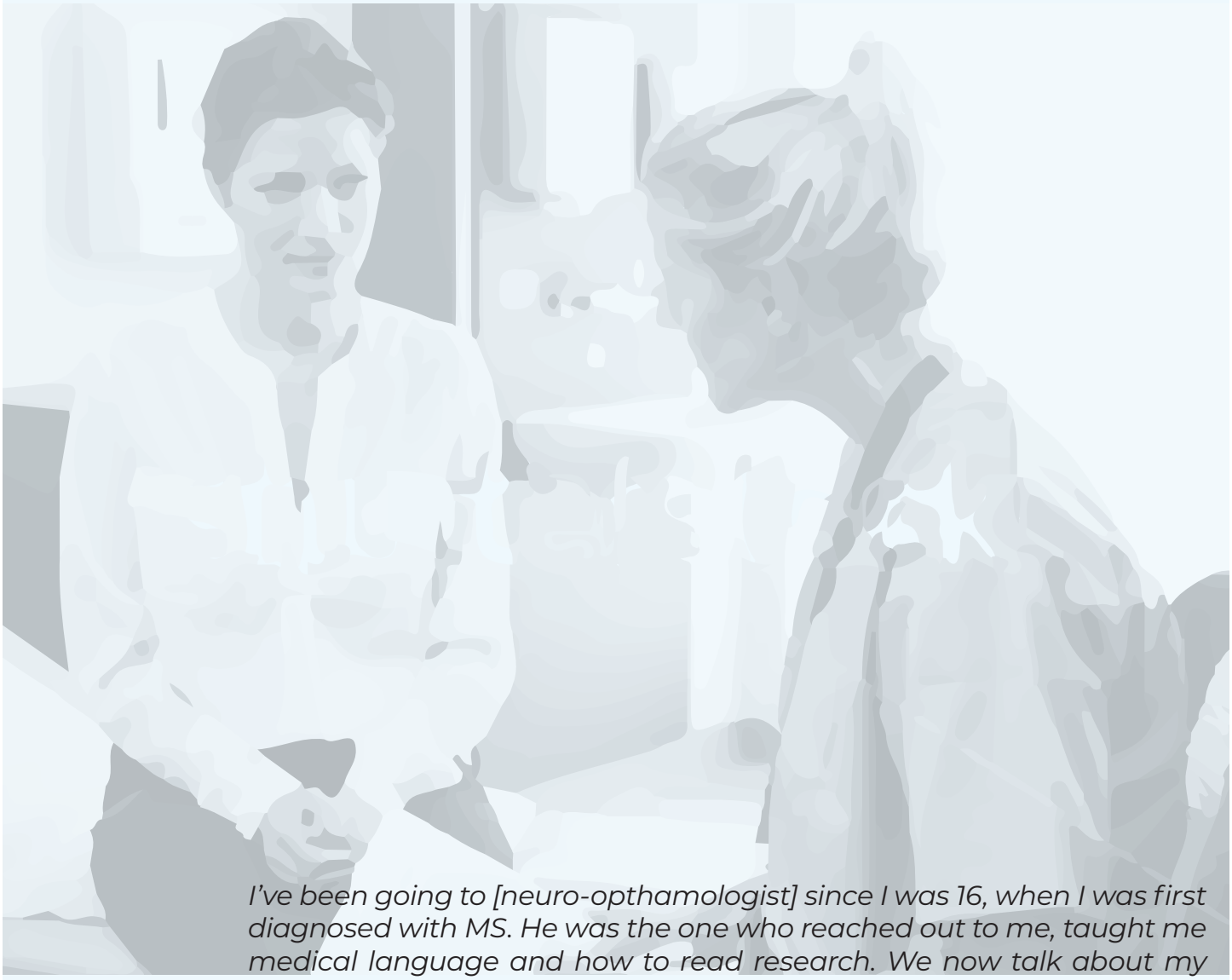
Despite being financially unsustainable and capable of producing poor health outcomes, many see industrial healthcare becoming more efficient, relying more on information and communication technology, and going "upstream" extending its reach to turn more healthy people into patients.

In industrial (or industrialized) healthcare, patients access healthcare and are processed.

About 40% of patients experience unsustainable burden of treatment, while 40% of clinicians experience burnout. When they meet, clinicians interrupt patients within 11 seconds and spend 40% of time with patients documenting care rather than caring.

Devoid of care, industrial healthcare is humanly unsustainable.

Furthermore, about 40% of patients experience unsustainable burden of treatment, while 40% of clinicians experience burnout. When they meet, clinicians interrupt patients within 11 seconds and spend 40% of time with patients documenting care rather than caring. As healthcare grows increasingly industrial, the response of patients and clinicians has been to lower expectations but there is a limit to this. Devoid of care, industrial healthcare is humanly unsustainable.



I've been going to [neuro-opthamologist] since I was 16, when I was first diagnosed with MS. He was the one who reached out to me, taught me medical language and how to read research. We now talk about my medical stuff, but also his kids, medical school and local Middle Eastern restaurants. Our appointments now seem like a balance between a friendship - a mentorship actually - and finding common ground, instead of just a medical appointment.

Patient living with Multiple Sclerosis (MS)
As told to fellow Melissa R'kingsley

The Words We Use

Defining Care

Care is both a disposition and a practice by which a person notices the problematic situation of another person and chooses to respond to advance that situation.

We refer to understanding that situation in sufficient detail to be able to respond well to it as being seen in high definition. Often people describe feeling seen and heard when this happens. Noticing involves recognizing not just needs but also strengths and assets that can be used to fight disease, build health, and enable recovery.

The clinician's disposition and decision to respond creates the possibility that the patient's situation can improve in their own terms. Responding with competence and compassion, clinicians can foster a partnership with the patient to co-create sensible solutions. For a care plan to make sense, it must respond to the problematic human situation as understood; must acknowledge and consider its emotional ingredients; and must be feasible to implement.

The patient as care-receiver determines the extent to which this care is appropriate, adequate, and minimally disruptive, that is, capable of advancing the patient priorities with the smallest possible healthcare footprint.

Over time, collaborations for care evolve into relationships akin to love in which patients and clinicians trust each other, make themselves vulnerable, and care for each other as persons. These enduring relationships offer resilience in the face of the inevitable disappointments that result from living with distress, disability, and disease.

Care is both a disposition and a practice.

Collaborations for care evolve into relationships akin to love.

For careful and kind care

Our movement seeks to turn away from industrial healthcare and to turn towards careful and kind care for all.

Careful and kind care is the care a patient gets when seen, heard, known, understood and helped. It happens when a clinician can notice the patient's situation without hurry, interruptions or disruptions and can respond with compassion and competence with care that makes sense, is maximally supportive of patient goals and minimally disruptive of their lives and loves.

Careful describes care by a which a clinician (a) notices the patient situation in high definition, in all its biology and biography, in its signs and symptoms and in the experience of illness; (b) draws from the best available science about conditions, tests and treatments as well as from the expertise and experience of patients and clinicians to further understand the patient situation and to figure out how best to respond to it; and (c) co-creates a plan of care with each patient that makes intellectual, practical and emotional sense to that patient.

Careful and kind care is the care a patient gets when seen, heard, known, understood and helped.

Kind care describes care that treats each person as they would like to be treated (the so-called platinum rule). It starts with curiosity and is respectful of the limited time, energy, and attention patients much rather invest in their lives and loves.

Kind care also recognizes the common humanity of clinician and patient rejecting the stigma and othering that often accompanies disease, deterioration, dysfunction, destitution, and dying.

The Words We Use

A note on language: patients and clinicians

The words we use not only reveal what we think but also shape what we think and do. A movement for careful and kind care must make explicit choices about language.

We recognize that healthy persons often approach healthcare for help. We also recognize that, even when sick, people are much more than their diseased bodies or mere passive recipients of healthcare. Industrial healthcare offers consumer, user, or customer service. We use patients to denote persons who need, seek, and deserve health care.

We use clinician to denote any prepared person (often a certified healthcare professional) who has the privilege of responding to the health care needs of patients. This encompasses physicians, nurses, nurse practitioners, physician assistants, pharmacists, therapists, and others in roles of care. Clinician places caregiver and patient in proximity, by the klinē or bed.

Industrial healthcare often uses providers to denote a person or an organization that delivers healthcare service. While providers deliver healthcare, clinicians care. Care is already a verb.

The words we use not only reveal what we think but also shape what we think and do. A movement for careful and kind care must make explicit choices about language.

Language as activism

Each of us can decide what language to use to describe what we have and what we want instead. The choice of language is an individual act of rebellion only briefly, ending its solitude the minute someone else opts for the same words.

Industrial healthcare uses expressions that objectify the patient describing situations as if they were inherent to who they are as persons or place them in adverse (or adversarial) light: “non-compliant,” “high-utilizer,” and “frequent flyer” are examples. Along with these, we must abolish expressions that promote indifference and cruelty and hinder a caring response.

Language can also be used to impair communication by promoting an insiders’ jargon comprised of words with specialized meaning or by abandoning or replacing words related to care. Industrial healthcare speaks of profit and value more than of care and love.

We must abolish expressions that promote indifference and cruelty and hinder a caring response; “noncompliant,” “high-utilizer,” and “frequent flyer” are examples.

The language of care must permeate clinical care records and health certifications, public announcements and wayfinding signs, policies and documents.

The language of care must be welcoming, and signal belonging, trusting, and partnering. It must be clear and precise, must be humble and acknowledge uncertainty, must express competence, compassion, and kindness, and must use silence judiciously to enable comfort and healing.

The Outcomes of Our Movement

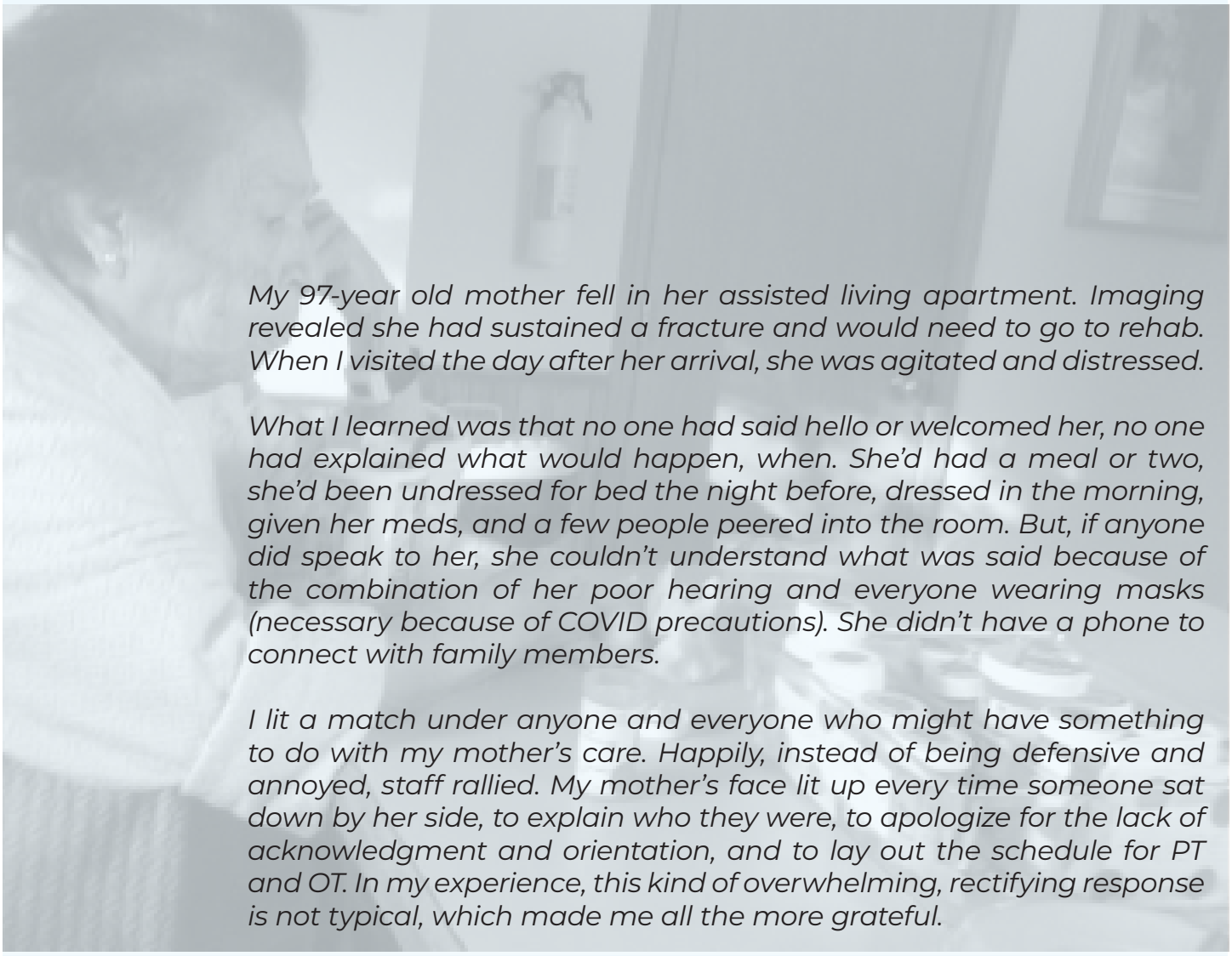
Evidence of Progress

A fundamental change from industrial healthcare to careful and kind care for all manifests as (a) a change in direction in accountability and in the relationship between money and mission, and (b) in the resolution of hurry, blur, cruelty, and burden, the so-called pathologies of care. We should notice these changes particularly in the care of the undercared.

Industrial healthcare holds patients and clinicians accountable for the care provided, produced and documented. Payers hold healthcare organizations accountable and managers within these organizations hold clinicians and patients accountable for meeting contracted targets for the consumption of certain services and the achievement of certain markers of disease control. Clinicians receive financial and reputational incentives; patients are reprimanded or fired from practices when they don't do their part, comply, adhere, show up on time, or improve markers of disease control. **Progress will be evident when patients and clinicians can hold managers, organizations, and payers accountable for the conditions for care they create.**

A fundamental change from industrial healthcare to careful and kind care for all manifests as (a) a change in direction in accountability and in the relationship between money and mission, and (b) in the resolution of hurry, blur, cruelty, and burden, the so-called pathologies of care.

Many organizations take part in industrial healthcare as businesses, set on making money by providing healthcare-related services. Other organizations are mission-oriented, that is they participate in industrial healthcare primarily to offer care. The money they make offering care supports improvement in the quality and reach of their services. Their leaders know "no money, no mission" and seek to make more money to realize the organization's mission. Industrial healthcare makes these two types of organizations indistinguishable, as mission-oriented organizations expand their mission in lucrative ways to make more money and restrict care from less lucrative patient groups, tests, or treatments. More mission, more money. Although financial sustainability is critically important, no organization in healthcare should be profitable while care-less. **Progress will be evident when healthcare organizations of any kind organize their operations, funding, and other resources first and foremost to realize their care mission.**



My 97-year old mother fell in her assisted living apartment. Imaging revealed she had sustained a fracture and would need to go to rehab. When I visited the day after her arrival, she was agitated and distressed.

What I learned was that no one had said hello or welcomed her, no one had explained what would happen, when. She'd had a meal or two, she'd been undressed for bed the night before, dressed in the morning, given her meds, and a few people peered into the room. But, if anyone did speak to her, she couldn't understand what was said because of the combination of her poor hearing and everyone wearing masks (necessary because of COVID precautions). She didn't have a phone to connect with family members.

I lit a match under anyone and everyone who might have something to do with my mother's care. Happily, instead of being defensive and annoyed, staff rallied. My mother's face lit up every time someone sat down by her side, to explain who they were, to apologize for the lack of acknowledgment and orientation, and to lay out the schedule for PT and OT. In my experience, this kind of overwhelming, rectifying response is not typical, which made me all the more grateful.

What made it possible for my mother to be ignored until I intervened? By way of apologizing, one staff member said "Most people when they first get here want to be left alone - they're relieved to be out of the hospital, want to rest, and they're not ready to go to work to get better." I said, "Well, that's not my mother. She's eager to get back to her life." This patient here, her name is Elaine.

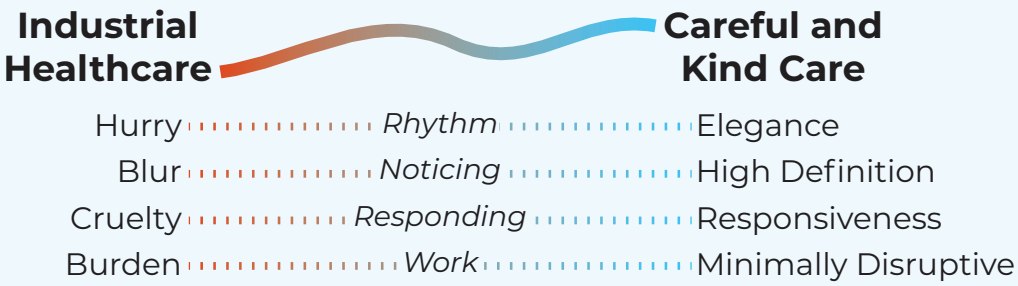
Shared by fellow Madge Kaplan

The Outcomes of Our Movement

Abolishing the pathologies of care

Progress will be evident when health care abolishes hurry, blur, cruelty, and burden.

Progress will be evident when health care is “elegant”, with no waste or haste, “focused” on the biology and biography of each person, “responsive” to each patient’s problems, and “minimally disruptive”, of patients’ lives and loves.



Abolishing...		Requires moving toward...	
Hurry	Requires paying attention to the rhythm of care. It requires recognizing where efficiency means more "patient care" in less time, where "time is money" produces rigid schedules, and where time in rushed encounters, with little patient and clinician participation, is spent in care documentation rather than on caring.	Elegance	Seeking an ethos of 'no haste and no waste'. Visits are scheduled flexibly to enable unhurried (neither longer nor slow) consultations while removing interruptions, reducing friction, and eliminating distractions.
Blur	Requires recognizing people responding to symptoms or test results without regard for the whole person. Where care plans are motivated by adherence to standards for 'patients like this' rather than by responding to 'this patient'. Where data and decisions are driven by what is salient for the system, instead of by what is important and yet 'mundane and common' (inconveniences, suffering) for patients which remain largely unmeasured and unattended.	Seeing each person in high definition	Seeking to understand both the biology and biography in a patient's situation and responding knowing what matters to each person
Cruelty	Means recognizing where the enforcement of policies breeds conformity that leads to indifference to the specific needs of each person. Where disengaged staff responds with 'it's not my job, or I'm just doing my job'. Where burnout and turnover results in resiliency programs and other interventions that locates problems in staff rather than in the system.	Promoting responsiveness	This means valuing staff for their integrity, diverse expertise and experiences, giving them authority and discretion to respond to the needs of each patient. It means eliminating policies and practices that get in the way of care and lead to indifference. Means caring for staff to enable staff to care - 'care in, care out'.
Burden	Requires detecting where efficiencies are achieved by delegating burdensome administrative tasks and medical errands onto patients and caregivers: where patients must repeatedly communicate their concerns, facilitate communication and coordination across clinicians and organizations, negotiate disagreements between clinicians, correct errors in documentation, close administrative loops, and follow up on tests and consultations themselves.	Minimally disruptive care	Co-creation of care plans that can be feasibly implemented without overwhelming the capacity of patients and caregivers, eliminating non 'value-added' activities, removing administrative barriers as a means of managing the demand for services, and simplifying and assisting with navigation.

CULTIVATE CARE

From Hurry to Elegance

Care has its own tempo: accelerate it and clinicians cannot notice patients in high definition or work with them to formulate plans of care that make sense. Care becomes accelerated when the duration of the visit is too brief for what needs to take place, for example when it starts later than expected and has a hard stop (because the parties have to be elsewhere, including subsequent clinic appointments), when the patient brings complex issues that require deliberation into a brief appointment, when the interaction is interrupted by accident or by design (by "requests" from the medical record system), or when there are items forced into the agenda that crowd out the agenda of care that patients or their clinicians must consider.

Unhurried conversations do not have to take long, and do not have to take place all at once, with narrative threads carried across interactions assuming continuity of the relationship.

Unhurriedness is sometimes achieved by slowing down, but slow down too much and hurry will be necessary elsewhere and waste becomes an issue. Unhurried conversations are elegant, i.e., no waste and no haste. They may even be efficient, in that issues may be more likely to be addressed correctly the first time, preventing rework and dissatisfied patients from rejoining the cue. Unhurried conversations may, at some point, take place at the expense of timely access to care. This trade off needs to be made explicit and a balanced approach negotiated with the community. The inverse-care law would suggest that unhurried conversations will be more likely to be accomplished in the care of the well-off, requiring efforts to achieve this with equity.

The unhurried conversation may be the simplest and most significant act of uprising against industrial healthcare.

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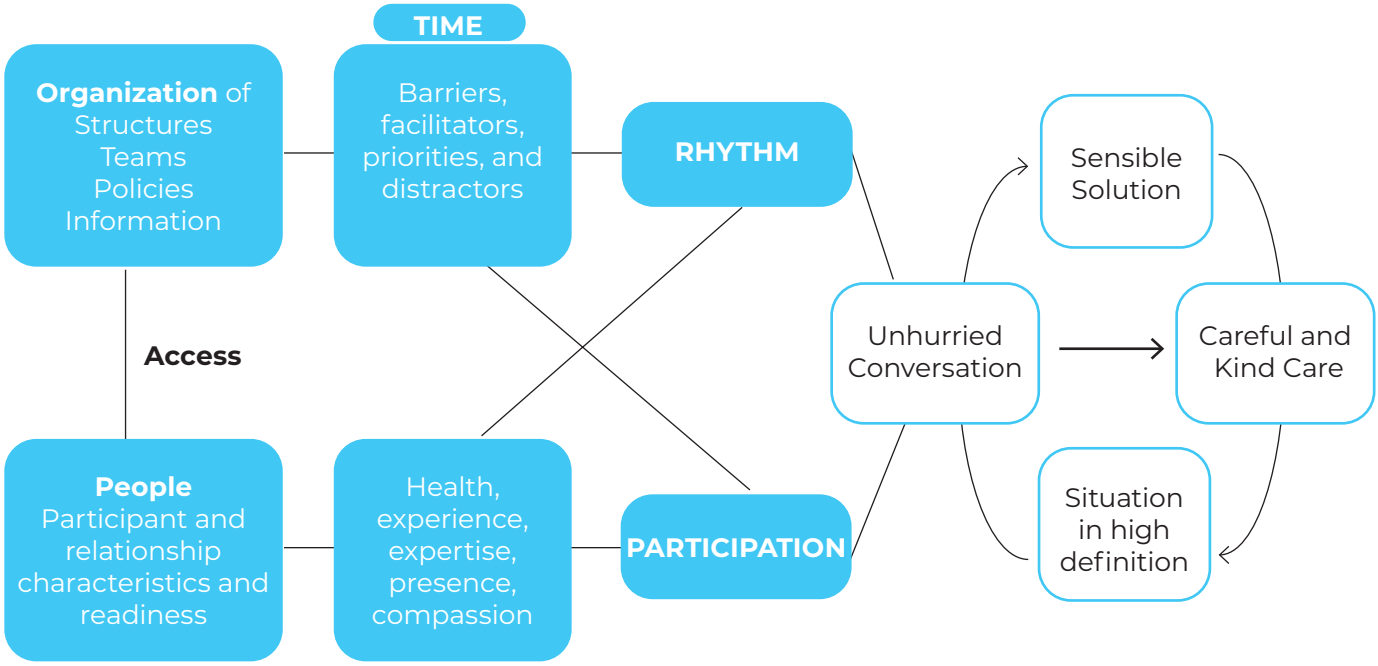
To achieve unhurried consultations is an accomplishment of the people involved and of the systems that are put in place, ultimately reflecting a culture of care manifested in the way people schedule, conduct, and appraise consultations.

The journey from hurried and rushed interactions guided by a priority placed on access, efficiency and throughput to unhurried consultations that enable careful and kind care reflect a change in values and priorities that must result from conversations among clinic staff and between the clinic and the community it serves.

A Preliminary Model of Determinants and Consequences of Unhurried Conversations



These conversations should produce a commitment to orient the clinic toward care and agreements among staff and between the clinic and the community about,

- how this commitment will manifest in the collective effort placed in achieving increasingly better levels of unhurried consultations,
- a language used to describe how consultations are scheduled and how their tempo is appraised, and
- a way of thinking and resolving conflict and inevitable tradeoffs (e.g., continuity and unhurried interactions vs. timely access).

Seen in this way, achieving unhurried conversations is not just the development of a method of care, but a reflection of our collective success in honoring our commitment to care, made to each other and to the community served.

Where to Start

Defining the undercared

There are patients and clinicians at higher risk for experiencing the pathologies of care and their ill effects. We propose that fundamentally changing healthcare can improve their situation and create the conditions for the emergence of care for everyone else. Thus, our movement must focus on patients most likely to experience the pathologies of care, the undercared, and the clinicians that care for and about them.

Industrial healthcare's capacity for indifference and cruelty affects people across the spectrum; those excluded from accessing or affording basic healthcare, and those with the privilege (and in more enlightened societies, the right) to fully access and afford healthcare.

Being sick and not being able to access care is the worst form of undercare. The reasons for excluding people vary by society and health system: greed and profit seeking, austerity policies, and discrimination, bias, and neglect against racialized people, foreigners, women, the uneducated and the poor. These social determinants of health are also the social determinants of healthcare and, therefore, of undercare.

Our movement must focus on patients most likely to experience the pathologies of care, the undercared, and the clinicians that care for and about them.

People who receive too many healthcare services can also be undercared. Overdiagnosis, overtreatment, and overuse of preventive, function enhancing procedures, and end-of-life care lead to downstream harms. Too much medicine indicates too little care.

Industrial healthcare responds poorly to patients living with ongoing physical and mental and emotional conditions, who often live in complicated psychosocial situations. These conditions and treatments interact with each other rendering the patient's problematic human situation complex, confused, and confusing. These patients need ongoing relationships, continuity of care, and highly coordinated care that continuously responds to changes in this situation.

Patients who are ill with symptoms that escape classification and diagnosis or don't respond to treatments with complete relief are also often undercared. They frustrate the routine ways industrial healthcare responds, often without noticing. Professionals, who are often themselves burned out and who cannot find a response in their training or within known clinical pathways, respond with a battery of tests and referrals. When these cannot reveal an objective abnormality as explanation for patient suffering, patients are stigmatized or turned away. Patients with unexplained medical syndromes often receive too much healthcare and too little care.

Prioritizing the undercared person

Nothing challenges the industrial healthcare's vision, mission, and values statement about care more than a suffering patient who cannot be readily helped with more biotechnology. Industrial healthcare cannot find efficiency in the work of a clinician who realizes that her patient has a better chance of recovering via presence, listening, kindness, continuity, and curious creativity; a clinician who is willing to partner with her patient and find, through trial-and-error, a way forward that can improve each person's ability to cope and adapt and, eventually, to thrive and live well.

Our movement for care must prioritize the undercared person. Improving the situation of the undercared person may offer the first and most clear evidence of the movement's progress.

Placing a priority on careful and kind care for those who are undercared may uncover initiatives with the largest impact as undercared people experience industrial healthcare's pathologies most often and most intensely.

Improving the situation of the undercared person may offer the first and most clear evidence of the movement's progress.

A priority for these patients will uncover the blind spots of current quality and value assessments that focus on "delivering" recommended care and achieving targets of specific disease control. Instead, it will promote primary care, palliative care, trauma-informed care, rehabilitation and physical and mental health therapy, and other forms of care that are often underused and undervalued.

Focusing on the care of the undercared person directly challenges the systems that have been perfectly designed to under-care for these patients and, eventually, for everyone else. This focus also aligns our movement for care with other movements seeking more humanly sustainable societies that are more inclusive and fairer.

While our goal is to fundamentally change healthcare, initiatives and innovations of our movement motivated by the plight of the undercared person can make a tangible impact in the lives and living of these patients even before our full success.

We also need Common Care

Leading the work to promote common care

Our movement for care must face two healthcare challenges: the lack of time for care and the necessity to be responsibly efficient with limited and shrinking resources.

There are two ways to address these challenges: We could grow the healthcare offer by investing more resources into healthcare (in countries who have shrunk this investment under a misguided austerity), substantially curtailing profit extractions and corruption, or both. Or we could reduce the demand for (professional) healthcare.

Demand for healthcare should not be reduced by excluding people (immigrants for example) or by placing access barriers (through paperwork and pre-authorizations by payers, narrow eligibility criteria, service closures and reduction in service hours) both of which cruelly preserve access for the affluent and the not-so-sick. Yet, these are the strategies currently in use, mostly to increase access for patients who go on to receive profitable tests, procedures, and treatments and to reduce the cost to payers and increase their profits or their sustainability.

Caring for, about, and with each other is a social determinant of health.

To reduce the demand for healthcare we will need both political and public health approaches to remove biological and social risk factors for distress, disease, dysfunction, and death or to at least to mitigate their impact.

Our movement must also lead actions to expand common care as a just way to reduce the demand on healthcare and enable the conditions for unhurried conversations, to reduce blur, and to advance careful and kind care.

Common care is the hard work of accompanying, alleviating, assisting, and attending to others. It is the ability and disposition of every person to make the personal, social, and material worlds of another person more able to support their human flourishing. Caring for, about, and with each other is a social determinant of health. Healthcare is just the epitome of this societal commitment to common care. At the same time, common care is necessary to reduce the demand for healthcare and create the conditions for care to emerge within healthcare.

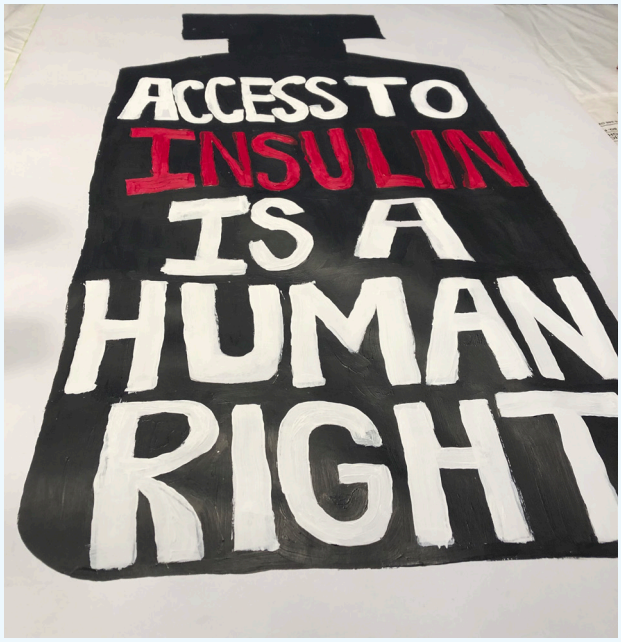
To promote common care, our movement needs to contradict current trends. Care is undervalued, so is acquiring and mastering the skills needed to care for others. Instead, all health concerns are believed to require professional care (as all health concerns become medicalized). Perhaps healthcare has inadvertently discouraged lay people from acquiring and using common care skills, for example, by disparaging online searches or condemning delays in seeking healthcare. Care is outsourced to someone else, frequently to women, and increasingly to low-income, immigrant women from ethnic minorities.

To promote common care, we must support it materially, financially, and socially. Valuing the use of these skills requires changing how we work. Acquiring and mastering care skills must be proudly celebrated. The responsibilities of care should be distributed more equitably.

CULTIVATE CARE

Ways to take Action for Common Care

- Increase the capacity for care in your community by acquiring skills and sharing the care skills you have with others;
  - train to be a doula/train others to be doulas
  - take overdose prevention training
  - learn CPR/teach CPR
  - take bystander training
  - facilitate a support group
- Volunteer and support mutual aid programs in your communities
- Develop programs that address particular needs in your community
- Support the people and spaces in your community that offer a respite from care. Community gardens, social clubs, sharing spaces, support groups. Caring for others can take its toll
- Join social and ecological justice movements
- Advocate for policies that enable common care, such as unconditional basic services or universal basic income, and increase the recognition – social and economic – of those who contribute to care.



THE PATIENT REVOLUTION

RESOURCES

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The conversation continues.

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