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EDITORIAL

Health care isn’t a lost cause: We can effect change, one story and one experience at a time

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SUMMARY

It may seem like everywhere we look, there is something wrong or “broken” in health care. Articles published in *The Journal of Health Design* (*The JHD*) reflect 13 incredulous, yet unfortunately “sad” realities about the state of health care that are evident worldwide. There is reason for hope, though, as important research and experiences published in *The JHD* convey. Much can be done to improve the patient experience, one story and one experience at a time. We provide a platform to share those important messages.

Key Words
Health care; patient experience, patient advocates; innovation; publish for free

INTRODUCTION

Three decades ago, and as a proxy for the quality of health care worldwide, the median time from diagnosis to treatment in the United States increased for all cancers. The time from diagnosis to treatment was significantly longer at National Cancer Institute Comprehensive Cancer Centers and Veterans’ Administration institutions versus community hospitals.[1] Since 2005, trends have continued on this trajectory with yet another report, which concluded that Time to Treatment Initiation (TTI) has lengthened significantly and is associated with absolute increased risk of mortality in early-stage breast, lung, renal, and pancreas cancers.[2] Even more recently, a study involving almost 2.5 million patients reported that people with breast, prostate, non-small cell lung, and colon cancer, generally had higher all-cause mortality and was associated with increasing time to treatment, depending on the cancer type and stage.[3] Meanwhile nations, especially the US, are spending more than ever on health care. It is now an eye catching $4.1 trillion or $12,530 per capita.[4]

Despite spending more on health care, some proxy measures suggest that patients are experiencing poorer outcomes, at least in terms TTI, and by corollary, recording poor survival rates. Increasing resources are clearly not driving the desired outcomes. The detail of how patients are supported from the point of presentation to definitive treatment needs more attention. In practice, the pathway of each patient through health care varies, so that the reasons why things are better or worse for some patients may reflect local and regional matters. Only those who are present in the private room in which patients come into contact with healthcare professional can explain why things do not work out as they should. There are established approaches on how patients and professionals have their interactions in health care recorded alongside the outcomes of diagnosis and treatment.[5]

At *The Journal of Health Design* (*The JHD*) we have been publishing the experience of patients, patient advocates, and clinicians. We have also shared patients, advocates, and clinicians' experiences through interviews on *The Health Design* podcast. Common themes shared in their published articles and in our podcast conversations include the following:

1. It is still possible for a healthcare practitioner to interrupt you in less than 30 seconds or to give you a challenging diagnosis while you are still under the influence of an anaesthetic or lying semi-clad on an examination table. It is still possible to have your ideas, expectations, or concerns dismissed, and for your choices as a patient to be overruled or invalidated. This might mean patients are not offered all options for treatment.

2. Despite advances in medical technology, it is possible that the practitioner can spend more time entering data into an electronic health record for legal or business purposes, or peering at an X-ray or similar, than focusing on the patient or exploring the context in which that patient came to be ill.

3. In 2022, it is still possible that some patients will be denied the right to define their gender or have their gender taken into account when it comes to treatment or any of health care's response to their predicament.

4. It is still possible for patients to have to spend time seeking out information on "Dr. Google", instead of being guided to sources of information and support. Patients may/will discover patient advocacy and support organisations by accident.

5. It is still possible that some patients will be treated as "disadvantaged" in health care because of their race, religion, or culture—and the cost to them and society generally will be huge.

6. It is still possible for patients and advocates to be sidelined and to be asked by conference convenors, journal editors, or policy makers to pay for others to benefit from the priceless information on how things can be improved to save lives and, by corollary, earn money.

7. In 2022, there are still doctors and nurses working in dreadful conditions that erode their talent and their problem-solving capacity. Doctors are burning out at a higher rate than ever before.[6]

8. In 2022, it is still the case that research is not delivering on the one outcome that matters—improvements to health care based on what science has already shown as having the scope for immediate benefit.

9. Despite the rhetoric around prevention, even in the wealthiest countries access to fresh food and cheap medicines is limited in the most vulnerable communities. Places with the highest rate of death and disability from preventable conditions are denied these simple measures.

10. Despite all the advances in medicine, it is still possible for people with signs and symptoms of advanced disease to have a diagnosis made when it is almost untreatable and for patients like those to have to advocate for themselves, despite living with life-limiting illness.

11. In 2022, some healthcare organisations look and function like a bus depot even when cheap and effective measures such as better communication skills or attention to detail of the fabric of the building have been identified to get the best experience for all.

12. In 2022, it is still the case that vast amounts of money are wasted on research with no scope to improve health—rather the money spent "oils the machinery" of academia.

13. In 2022, it still costs a fortune to publish or access research in the "established medical journals" and to have to pay to attend conferences to hear the same tired messages that have brought us to this state of affairs.

Many adjustments are needed if health care is to deliver on its potential to make an even more positive impact on the lives of the people it serves in every country. For that to happen patients need to be the driving force for innovation in health care. Without a patient-centric approach people will continue to struggle, and the burden of illness will continue to be multiplied by the stress of having to deal with matters that health care can make easier to bear.

One solution is for advocates, in partnership with clinicians, to fill the gap that health care fails to bridge—namely, the need for information, support, and advocacy. In addition, there is an opportunity for providers to espouse a different model that takes into account these key things: the need for excellence in communication skills; the need for attention to detail in the way a room is furnished for the interaction between health professional and patient; rehearsed set plays (scripts) for how health care responds to the needs for explanation; and the presentation of choices that are available in every medical encounter.

This alternative model is possible at a local level and by leveraging the opportunities that may be unique at a specific location. By exploring patient or clinician insights—types of articles we publish—*The JHD* will continue to document and share what is possible given the will to foster and promote a way of healing that always has been, and will continue to be, possible.

The JHD is an independent, open access healthcare journal committed to publishing articles that have undergone rigorous "double-blind" peer review. We believe in "small changes, big impact", and we are a platform to give a voice to those with something important to say that could improve the way health care is delivered, how doctors communicate with their patients, and how patients are heard so their specific needs are met. In 2023, *The JHD* will redouble its focus on what is already possible. The key features to note:

1. *The JHD* is free. Authors retain copyright, and all articles are openly available.

2. Submitters will receive thoughtful and helpful feedback from reviewers who are experts in their field and care about making health care better for everyone.

3. We will encourage. We are not an anonymous editorial office that cranks out rejections due to "limited space".

4. Authors will receive support from the editorial team throughout the publishing process. We always work with authors to help them get published rather than finding a reason to reject. All articles accepted for publication will continue to go through a two-round editing process to ensure the final manuscript text flows and is clear.

5. Our articles will be available on Google Scholar, DOAJ, and Index Copernicus. Being published in *The JHD* will count toward your key performance indications for publication where that is relevant or helpful.

6. *The JHD* will again publish three times a year. Published authors may also have an opportunity to talk about their work on *The Health Design* podcast, to present at our Linkedin Global Mini Conference, or to publish videos or infographics to assist others to emulate the lessons learned.

There is much that can be done to improve outcomes in health care. At *The JHD* we acknowledge that those who work in health care or experience it firsthand are best positioned to drive the necessary changes. We are honoured to serve you.

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