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Patient experience a vital consideration in crafting solutions for healthcare challenges

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EDITORIAL

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Healthcare providers around the world face the same challenges. Broadly speaking, they include five key issues: access to health care; prevention of chronic and complex conditions; reducing the burden of iatrogenic disease; supporting people with established chronic diseases; and tackling obesity. I have put the latter issue in a category of its own because it is probably the most significant challenge to health care in the developed world and is increasingly a marker of poor nutrition elsewhere in the world.[1]

In most cases health care, especially the government-subsidised kind, continues to be delivered via the services of a doctor. The patient first attends a generalist who will determine the best course of action, including if referral for more specialised and therefore more expensive treatment is necessary. In making this assessment of the patient's need, *context* is everything. The following may apply in assessing outcomes in relation to the practitioner-patient dyads:

1. The age and gender of those involved.
2. The social, political, and economic conditions.
3. The history of both in the lead-up to current events.
4. The culture of both.
5. The practitioner's professional interests.
6. The ideas, concerns, and expectations of both.

At the same time, in most cases in general practice what the practitioner offers has only a peripheral impact on the outcome. Most minor self-limiting illnesses will resolve spontaneously. However, there is a significant risk that inappropriate treatment, or for that matter any prescribed treatment, could do more harm than good. The outcomes are similarly dependent on the ability to practice the art of medicine.

Demand for health care

The first and most important question is: why has this person sought the help of this practitioner at this time? If the practitioner does not know, then he/she is unlikely to be able to say if what subsequently transpires is for the best, or if it failed, why it failed.[2] The context is often locally and personally defined. Any successful attempt to improve outcomes in health care requires attention to context. This is the essence of what I have coined "*Patient Experience Design",* the design of innovations where the main goal is to improve the patient experience. It is also why general practice, with a focus on holistic and continuing care, is at the heart of the best health care systems in the world and why progress in health care will be determined by shifting the focus from policies and systems to individuals and relationships.

Data are important, but no innovation can be deployed without the lens of context. For example, upper respiratory tract infections are the most common reason that patients consult doctors in primary care. What can doctors do about these infections? In the vast majority of cases, nothing. And still patients come in the hundreds of thousands. We know that there are some effective over-the-counter symptom relievers. But for many people the runny nose and aching limbs is more than they can cope with on top of boredom, anxiety, and that hour-long commute on a crowded bus to work at a job that only just pays the bills.

For those who choose to stay off work, their employer may demand a "doctor's note". That will then lead to a medical consultation. Accordingly, upper respiratory tract infections more than any other medical condition teaches us that context is everything in medicine. For the medical practitioner it is not a case of treating an infection, it is about seeing the patient within the backdrop of his/her life. The common cold offers an uncommon opportunity to connect with some people who are then moved to declare their unhappy life circumstances.

When we frame the epidemiology of respiratory tract infections as a microbial assault, it is like attempting to navigate a route with reference only to "Google Earth".[3] The impact on human behaviour is only discernable in finer detail. Perhaps people consult doctors in these circumstances when there are many other things that are wrong in their lives. The medical response to upper respiratory tract infections can best be crafted with reference to *Patient Experience Design.* The patient requires more than platitudes about a "viral" illness that does not respond to antibiotics. The time out may offer an opportunity to reflect on more fundamental problems. The best response in medicine may be to acknowledge the "troublesome" symptoms and accept the reasons for consulting without harming the patient with unnecessary drugs.[4] To do this well and to promote a more resilient attitude to discomfort requires an understanding of what people need when they are suffering but not moribund. Those with upper respiratory tract infections who seek help are not malingerers because more than a virus causes their morbidity. As well as an opportunity to stimulate reflection on what ails them, more generally it is a teachable moment to instruct on self-care.[5]

Regarding access to health care, a perennial issue appears to be the rising demand at hospital emergency departments (ED) in most hospitals. Administrators remain concerned that the patients choose hospital when they could more appropriately be served in the community by a general practitioner. Why do people with seemingly "minor" infections present to a busy emergency department? There are plenty of data but no explanations. Speculation results in misleading conclusions and ineffective attempts to change behaviour. In reviewing this issue we might consider:

- Was it really easier for people to consult a GP on a same-day basis?
- Why were they more inclined to attend an emergency department that may be busier by the day?
- What are the ideas, concerns, and expectations of people in the waiting room of the ED?
- What triggers a visit to the ED?
- What experience in the ED sends a message through the community that this is the place to be when you are feeling unwell?
- What experiences in general practice appear to send the message that it is better to go to the ED?

According to BJ Fogg three things must be aligned in relation to behaviour: motivation, ability, and a trigger.[6] The result of these factors must make it more likely that people will rush to an ED rather than make an appointment with their GP. The reasons why demand at EDs is increasing begins with an understanding of the context in which that trend is taking place. An alternative outcome can be designed with reference to considering the patient experience. Such information can be gleaned directly from the patients but also from the ED staff, the local GPs, and especially their receptionists.

In a study of adult ED attendance, we concluded that any attempt to reduce attendance would be challenging.[7] Attenders to EDs are not a homogenous group. Most people who attend an ED do so relatively infrequently and those who attend most frequently tend to be in greater need of emergency services.[7] On the other hand, frequently attending children may be a very different case where interventions may be more fruitful because minor illness tends to be a more frequent reason for attendance.[8]

As always, context is key and, as always, there can be no policy making before we fully appreciate what we are observing in these data.

Obesity

There is increasing evidence that overweight and obesity exists in the context of families. There may be something about family dynamics that engenders or maintains the problem with excess weight gain.

1. A 2004 study in the *Journal of Pediatrics* found that the biggest factor that predicted children being or becoming overweight was if the parents were also overweight.[9]
2. Other research found that two-thirds of parents underestimate the BMIs of their children, especially when their children are overweight or obese.[10]
3. Some data have even suggested trends according to the relationship of the adults in the household: "*Non-poor children living with married step-*

> *parents had a 67 per cent higher risk of obesity compared to similar non-poor children raised by married biological parents."*[11]

The study authors could not explain why children in married parent households had lower probabilities of obesity. The final word is:

> *Information on children's health and nutrition must reach not only mothers, but the other caregivers (relatives, fathers, step-parents) with whom mothers and children regularly interact. It is also important to ensure that caregivers are in agreement about issues of nutrition and physical activity for children.*[11]

Innovations to tackle obesity need to consider the context in which the person with the problem is presenting for help. That person is someone's son or daughter. What else are they coping with? Could anything the practitioner have done reduce their status to someone who fails to appreciate the first law of thermodynamics? If so, are practitioners going to make a bad situation worse?

Chronic and complex conditions

In a review of the impact of breast cancer on women's lives, a team of researchers reported one woman's altered perspective on her relationship with her partner as reported to her specialist breast cancer nurse (BCN).[12] The experience of breast cancer had altered her view on something she had taken for granted. Pre-cancer was very different to post-cancer. Subsequently, another team of researchers concluded that:

> *In the absence of cancer specialists, in years 3, 4, and 5 following diagnosis, Australian women would prefer to have their routine breast cancer follow-up provided by a breast physician (or a breast cancer nurse) in a dedicated local breast cancer clinic, rather than with their local General Practitioner.* [13]

Patient experience drives preference while, despite this evidence, nationally experts in cancer care have been actively promoting shared care between GPs and specialists.[14]

In a previous paper my team and I speculated that it is the relationship with the breast cancer nurse from diagnosis through treatment and beyond which makes her the preferred carer following treatment. At this time in most cases, the GP is hardly involved at all. Our data suggested that if the approach to patients in the period following active treatment was limited to discussing physical symptoms and possible side effects of adjuvant therapies, then there will be a lost opportunity to help patients to adjust to the experience of breast cancer. From our data we suggest that this would lead to psychological, social, or physical harm unless patients also find other sources of help. However, the importance of the BCN who has the experience and resources to support the woman throughout the process of readjustment but can also recognise the significance of clinical changes in breast tissue is a critical element of any follow-up protocol.[12] That does not mean to say it cannot be her GP, but the conclusion of research with patients is that often it is not.

Overall, BCNs play an important role in facilitating the transition of patients by supporting the woman in adjustment to a new self-image and bodily functioning. The BCN *accompanies* each woman through this phase in her life while supporting a new narrative, promoting her "rebirth" as someone with views that have altered significantly after the diagnosis of cancer.

Breast cancer, along with many other conditions where the patient is subject to treatment to combat a potentially life-limiting pathology, changes the patient's perspective forever. In crafting support for such patients, it may be crucial to consider what the patient has experienced and with whom and not what would suit healthcare providers to offer in the way of support. The follow-up regimen has to be tailored to the context. That word context again!

Consumer satisfaction

The experience of an illness, accident, or emergency can heighten the trust in a medical practitioner. Primary prevention is more problematic. People who are asymptomatic and being urged to alter their lifestyle or take antihypertensives may be less trusting.[15] Three factors appear to influence the attitude: age, socioeconomic status (SES), and prognosis. I was part of a team that conducted research with reference to cardiovascular disease. The data offered some helpful pointers on which patients are most trusting:

> *Older patients, lower SES patients, and patients with established pathology are more likely to trust, and are less likely to question medical advice.*[15]

Our research also suggested that:

> *Participants who perceived themselves at risk of a poor or uncertain outcome were unlikely to express doubts about medical advice.* [15]

Therefore, context is critical when crafting an approach to the patient. Does the patient wish to be involved in decision making or would the practitioner's presentation of multiple options with the relevant probabilities for each outcome make a bad situation worse? At a time when there is a push towards "patient self-management",[16] the data suggest that some patients prefer a traditional approach with the doctor recommending a particular treatment regimen. Older people in deprived areas top the list. This group is also at the highest risk of chronic and complex health conditions. Unfortunately, getting this wrong when the patient wants to be more involved may destroy the relationship between patient and clinician.[15]

We need to understand the business of doctoring as an integral part of designing solutions aiming to optimise patient experience.[17] We need doctors to step up as co-designers. Treatment is often determined locally within the appropriate context rather than a one-size-fits-all. The solution to health care challenges starts with having a good GP and continues with good research in the most influential sector in health care.

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