UPSIDE DOWN HOSPITAL: CO-PRODUCING SAFETY WITH PATIENTS

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Safety in healthcare has not significantly improved in the last 20 years with an estimated 5 to 10% of patients admitted to hospital suffering from adverse events. Health care is a service that can encourage optimal health outcomes only through meaningful, collaborative partnerships between patients and clinicians. Co-production of health services can be used as a means to rethink how health care is delivered with patients as co-creators rather than passive recipients of health care assisting healthcare organisations towards safer and more responsive care. Technology can improve patients' agency over their care when consumers are able to personalize their experience while using an organization's service and in return undertake specific tasks needed by the organization. Patients can be the pivot point of safer hospital care, not only in the context of face-to-face encounters in which the benefits of working together are obvious, but also in designing systems that can improve patient care, increase satisfaction and enhance the value of care.

Introduction

Safety is one of the five dimensions of quality in the delivery of healthcare. Studies from OECD (Australia, the US, UK, Denmark, Netherlands and Canada) as well as from low and middles income countries (Pakistan, India, Nigeria) suggest at least between 5 and 10% of patients suffer adverse events during hospital care. Up to 50% of adverse events are thought to be preventable (Hogan et al., 2012). The Institute of Medicine To Err is human" described the problem of error in healthcare and outlined steps to improved safety. (Kohn, Corrigan, & Molla, 2000) The subsequent report 'Crossing the Global Quality Chasm' (National Academies of Sciences, Engineering, 2018) stated that 1 in 10 patients are harmed in hospital care resulting in between 5.7 and 8.4 million deaths annually as a result of poor quality care. Fourteen out of every 100 patients are affected by Hospital Acquired Infections. Surgical complications lead to 2% of all patients undergoing 234 million surgical operations performed annually. 20-40% of health spending is wasted due to poor quality of care and safety failures with up to 15% of hospital costs attributed to patient harm caused by adverse events (National Academies of Sciences, Engineering, 2018).

Organisations representing healthcare professionals such as the Royal Colleges (Royal College of Physicians, 2019), World Health Organization (Barach et al., 2013), non-governmental organisations such as the Institute for Healthcare Improvement, public bodies such as the Australian Commission and legislators have made significant efforts to improve safety of healthcare by engaging patients at the micro-, meso- and macro-levels. However systems for compulsory training, accreditation and revalidation for professionals, introduction of cognitive aids and checklists for teams and policies aiming to strengthen quality control of organisations have done little to consistently improve quality in the last 20 years (Braithwaite, 2018). This contrasts steeply with the improvements built around modular redundancy achieved in other high reliability industries (Sanchez J; Barach P, 2012).

A growing body of literature supports Design Thinking, a human-centered approach to co-creation of process improvement, and improved patient experience design. Prototypes are iteratively created and tested with patients and parents of children undergoing complex surgery to gather meaningful feedback(Lopez et al., 2017) . Services designed this way are associated with higher satisfaction for patients, better clinical outcomes in numerous non-medical domains at a lower cost. Patients that are able to signpost effective mechanisms of healthcare delivery and co-designed services have better uptake rates (Batalden et al., 2016; Dineen, 2014).

In this paper we make the argument that applying design-thinking can be a powerful tool to understand patient needs and then conceive solutions to meet those needs. We identify patients as an overlooked and deep resource well for the re-design of safer systems for care in hospital. We aim to collate emerging evidence that patients understand their own safety in healthcare systems, and are able to strengthen the principle of modular redundancy that underpins many high reliability organisations. We hypothesize that changing the mind set regarding the contribution by patients to modular redundancy of hospitals' systems can make care safer.

Methods

This paper examines evidence in three parts: 1) Evidence for redundancy as a safety feature in healthcare systems, 2) Evidence for patients' engagement with safety in healthcare, and 3) Emerging evidence for patients contributing to systems' redundancy and resilience.

Assumptions: We base our work on the assumption that self-preservation is a key human characteristic that can drive the behaviour of individuals (Eriksson, Hildingh, Buer, & Thulesius, 2016) and their relatives (Egerod & Overgaard, 2012) and that this is a driver that is unique to patients. Our second assumption, is that patients and their carers already participate heavily in their own healthcare not on their own

but as part of the broader healthcare team. This mostly undocumented "patient work" narrows the task of finding ways to accelerate and shine a broader light on how patients can create safety as part of their care teams (Yin, Nathan-Roberts, & Barach, 2019). The participation of patients has been labelled 'the invisible work of patients'(Unruh & Pratt, 2008), and includes the monitoring and management of states of health over long periods of time by patients' relatives (Lagosky, Bartlett, & Shaw, 2016).

Definitions: For the purpose of this paper the term 'patient' is used to describe the end user of healthcare, a person with an acute disease or chronic condition who is receiving services by the healthcare economy. The authors appreciate that patients also receive healthcare outside the formal healthcare system where synonymous terms could be citizens, consumers or service users. 'Redundancy' describes the 'inclusion of extra components which are not strictly necessary to system functioning, in case of failure in other components' ("redundancy | Definition of redundancy in English by Oxford Dictionaries," n.d.) are thus equivalent and able to run contemporarily. Redundant systems are to be differentiated from 'back-up' systems that are only activated in case of failure of the primary system and are usually inferior to the primary system. The term 'redundant' can also be used to describe 'no longer needed or useful'("redundancy | Definition of redundancy in English by Oxford Dictionaries," n.d.), unneeded and superfluous systems. Modular redundancy is a key feature of high reliability organisations(Sutcliffe, 2011). Triple modular redundancy is typically used in aviation, nuclear power, manufacturing and other high reliability industries(Lyons & Vanderkul, 1962).

1. Critical review of the usage of redundancy in medical literature. Evidence for modular redundancy to enhance reliability in health care systems was examined through a critical review of the peer reviewed literature, grey literature and examples from clinical practice (Grant & Booth, 2009). A "scoping" strategy was adopted, with a focus on summarizing evidence and identifying gaps in the literature. The resulting question that guided our review was: "*In which clinical areas have has redundancy been used to enhance patients safety and how?"*

Data Sources: The critical review used the search terms 'redundant', 'redundancy' combined with terms denoting patient safety including the related MESH terms (("Patient Safety"[Mesh] OR "Risk Management"[Mesh]) AND ("redundant" [Abstract] OR "redundancy" [Abstract] OR "backup" [Abstract]) Sort by: Best Match). We searched for studies using the following full-text databases: PubMed (including MEDLINE), and the Cochrane Library. We used a snowballing technique by scourcing the reference sections of articles that we included in the review.

Inclusion and exclusion criteria: The search was limited to qualitative and quantitative studies that included adult or pediatric patients. Studies describing redundant cellular, genetic or physiological processes, redundant workings of laboratory devices and research protocols were excluded.

2. Critical review Patient Safety' and shared decision making, co-production, co-design. A critical literature review along the same lines as above was undertaken to examine the role of patients in co-producing safer care. Terms of co-production, co-design, co-creation and shared decision making were combined with MESH terms for patient safety ((co-design [Title /Abstract] OR co-production[Title/Abstract] OR co-design [Title/Abstract] OR shared decision making[Title/Abstract]) AND ("Patient Safety"[Mesh] OR "Risk Management"[Mesh]) Sort by: Best Match Filters: Clinical Trial). Only clinical trials that reported patient outcomes of patients admitted to hospital were included. Study protocols were excluded.

3. Case studies for patient involvement in safety in healthcare: Case studies that illustrate the contribution of patients and their families to safety of healthcare systems were summarised, predominantly from care delivered in hospitals.

Results

1. Critical review of modular redundancy in healthcare. A search of the literature resulted in 353 papers that used the term redundancy in the context of patient safety. A review of the Cochrane library identified 19 publications – none of the studies used the term redundancy in line with the inclusion criteria. Several publications (Kongsvik, Halvorsen, Osmundsen, & Gjøsund, 2016; Penchansky & Macnee, 1993; Trevino et al., 2018; Van Spall, Kassam, & Tollefson, 2015; Watkins, Tirabassi, & Aversano, 2006) reference generic principles of redundancy in safer systems as codified and adapted from Sutcliffe (Sutcliffe, 2011). The remaining manuscripts listed examples of redundancy to structures and processes of healthcare (Donabedian, 1988). At a structural level redundancy might be important for the set-up of viable rural health services (Kornelsen, McCartney, & Williams, n.d.), and to plan the evacuation of patients from healthcare facilities in case of an emergency (McGrady, Blanke, & Swanson, 2014). Descriptive manuscripts referenced redundancy in operating rooms (OR) as a necessary feature for essential equipment for tracheal intubation (Durbin, Bell, & Shilling, 2014), for broader intra-operative resourcing (Kolodzey, Trbovich, Kashfi, & Grantcharov, 2019), and in the performance of surgical checklists (Treadwell, Lucas, & Tsou, 2014). The World Health Organisations Safer Surgery checklist (Haynes et al., 2009) uses features of a redundant system by mandating the presence of whole teams (including patients) for a forcing function, briefing prior to surgery. Usage of checklists have been demonstrated to reduce adverse events in a number of studies but only when the intervention is seen as a social-technical and not merely a technical fix (Dixon-Woods, Bosk, Aveling, Goeschel, & Pronovost, 2011). The application requires engaging staff by respecting their awareness, and embedding the intervention into the culture of an organisation (Urbach, Govindarajan, & Saskin, 2014).

At the level of general care processes the importance of function redundancy was highlighted in a qualitative review of a wireless nurse call systems (Klemets, Evjemo, & Kristiansen, 2013). An observational study of in-hospital

transfers identified four redundant steps for communicating patients' infectious status with a low system reliability due to low reliability of each individual step (Ong & Coiera, 2010).

Medication safety relies on processes of 'social redundancy' in relation to release of medications by pharmacists and nurses (Tamuz & Harrison, 2006). The authors highlight that redundancy can increase systems risks if it "lacks independence, increases complexity, obscures operating processes, diffuses personal responsibility". This might explain findings in a report on medication safety from 35 hospitals in Maryland which indicated low scores in relation to redundancies and independent double checks (Kazandjian, Ogunbo, Wicker, Vaida, & Pipesh, 2009).

Our group has tested electronic monitoring systems with features of modular redundancy in clinical practice (C. P. Subbe, Duller, & Bellomo, 2017). An automated notification system enrolled 4502 patients and used a wireless autonomous recording of heart rate and respiratory rate in two high acuity areas in a secondary care hospital in an interventional pre-post study. Abnormal vital signs were graded and depending on the degree of abnormality were disseminated to 2-4 responders. Lower levels of vital sign abnormality were displayed to the bed side nurse and to the shift lead at the nursing station. Higher levels of abnormality were displayed to an advanced nurse practitioner with critical care skills and to the senior resident on call. The mortality on general wards, mortality after admission to critical care, rate of serious events and rate of cardiopulmonary arrests decreased significantly in the intervention group.

2. Critical review of patient involvement in system safety. Shared decision making is a formal way of making decisions with patients. A Cochrane review of 87 studies mainly from the USA, Germany, Canada and the Netherlands found that 44 studies evaluated interventions targeting patients using "decision aids, patient activation, question prompt lists and training for patients (Légaré et al., 2018). Twenty-eight studies targeted both patients and healthcare professionals. The certainty of the evidence of positive impact was thought to be low for both groups. Studies of co-production, co-design, co-creation and shared decision-making identified 39 studies, of which 38 were interventional trials. None of the studies identified reported safety outcomes and none focused on patients admitted to hospital. The Cochrane collaboration concluded little evidence for recommending co-production in acute care settings.

3. Application of principles of redundancy to support the roles of patients. In a published descriptive review of 24 case studies of patient harm, there was evidence in almost all cases for the presence of unchecked family or patient concerns (Johnson, Haskell, & Barach, 2016). Often the patient and family held complementary and vital information to that used by their healthcare teams about the state of the patients. One in five patients found significant errors in their EMR records (20%). An informal survey amongst colleagues of the authors found that the majority of healthcare professionals have serious concerns about their care or that of a friend or relative admitted to hospital, and they reported care was escalated by them when they bypassed the usual systems i.e., rather than alerting the nurse of their friends or relatives about a perceived care concern they directly called the intensive care unit or a senior colleague in the hospital or at home to request change in care. In these work around cases, healthcare professionals worked around the formal system and become informal care givers. This is recognized in hospitals that allow patient and family activation of Rapid Response Teams to great effect(Odell, Gerber, & Gager, 2010).

'Howz' ("Howz working with EDF Energy | Howz smart monitoring system - Supporting independent living," n.d.) is a smart phone application that links friends and relatives of frail or vulnerable patients to form a supportive dynamic social network. Participants of the network can post messages in relation to contacts with the patient ('*How's grandmother?'*) and help address safety concerns. The system can be linked to electronic devices and door alerts in the patients' home to allow monitoring of usual home activity such as switching on a kettle in the morning or the television in the evening. A formal evaluation of the impact on safety outcomes has not been undertaken.

Christian Farman is a Swedish dialysis patient with renal failure who in 2005 was allowed to run his own hemodialysis out of hours in order to pursue his job and have more control over his life. He soon taught other patients who also self-dialysed. Patients in the self-dialysis group had fewer infections, higher quality on their use of drug and were also more satisfied with their care. ("Institute for Healthcare Improvement: A Patient Directs His Own Care," n.d.).

In a quality improvement program developed by two large healthcare networks in the UK patients were informed about a risk of acute kidney injury (AKI). AKI is a common complication of other acute illness, resulting in reduced urine output and a risk of death of 20%. Patients were offered a bracelet with different urine colours and instruction to inform nurses of their urine colour every time they went to the toilet. Monitoring of urine output increased by a factor of 3 after the intervention (C. Subbe, 2015).

Social networks to support population safety has been part of a dedicated service by Facebook for disasters ("Facebook Crisis Response," n.d.). The webpage allows people to link up information about safety of individuals outside of a formal public service but we could not find any formal evaluation of this network.

Discussion

Health care is a service that can encourage optimal health outcomes only through meaningful, collaborative partnerships between patients and clinicians. Co-production of health services can be used as a means to rethink and reframe how health care is delivered with patients as co-creators rather than passive recipients of health care assisting healthcare organisations towards safer and more responsive care. We found only a few examples of effective application of modular redundancy in healthcare despite wide usage in non-medical, high reliability systems. The examples we found were limited

to the usage of checklists, medication safety and with physiological monitoring. Co-production of safety of patients is increasingly a part of public discourse without strong evidence in the peer reviewed literature, as of yet. Working from first principles and case examples it would seem that participation of patients in systems that support their safety is feasible and offers a powerful and low cost mechanism to enhance the system's resilience.

Characteristics of redundant systems. Co-producing value in health care starts from the fact that patients and clinicians exist within a larger system that can promote or impede progress toward optimal care. The systems that we found described a redundancy of documentation, communication and intervention in hospital and community settings. The structure of the redundant system was not always obvious. For example it was not clear how many participants or systems were operating in parallel. In high reliability engineering triple or quadruple modular redundancy is a typical feature and bedrock principle. Many medical examples have double modular redundancy or work with ad hoc networks that have a variable number of participants that are not entirely equivalent nor aware. The role of modular redundancy across social networks might require further examination. Support by family and peers is an important mechanism of safety for individuals outside the formal healthcare economy. These social networks are often dynamic both in the number of participants at any given time and in their constitution and support functions over time. Support is often dependent on reciprocity.

Future scope of patient and network knowledge. Social networks are a potentially attractive mechanism to assure safety of individual patients. Monitoring of physiological parameters usually compares vital sign measurements to previous measurements and compares it to what is thought to be normal values for a member of a given population i.e., a blood pressure measurement in primary care will be compared to previous recordings and to what is the recommended normal range and target range for treatment of 140/90 mmHg. In patients who have high blood pressure readings the previous values will be taken into account and a gradual lowering of pressures is recommended in those who are repeatedly above the normal recommended range. There are many softer measurements of well-being such as the pattern of mobility, the appetite of a person or their overall mood. These are important prognostic predictors but not readily measurable. For these parameters the knowledge of patients and those in their social network of what is considered 'normal for them' is the only way to monitor well-being, risk and recovery from illness. This knowledge is currently not systematically applied in healthcare.

Cost and Value. Redundant systems might be perceived as costly given the requirement for multiple actors with equivalent skills. The ability of patients to contribute to the functioning of the larger system might equally contribute to their overall care value, prevention of diseases, and overall cost effectiveness.

Drivers and governance of redundant systems. Redundant technical systems have defined mechanisms to assure the switch between redundant elements is reliable. In human systems reliability is often regulated by a hierarchy and lines of commands. Modular systems might not be arranged in a hierarchical way but require explicit rules of engagement to assure that the advantage of having several responders to a safety challenge invites the risk that nobody feels responsible, a well-known phenomenon in urban crime intervention. Motivation is an important part of behaviour. Arguably patients might have the biggest motivation but are rarely called upon to advance or contribute to their safety in healthcare. While the patient has been described as the most underused resource in healthcare systems (deBronkart & Sands, 2018) the 'how' of using the multiple emerging resources (Parish, 2015) to best effect, especially in traditionally strong hierarchical systems such as hospitals, will need experimental exploration. Implications for research and clinical practice

Conclusions. Patient surveys and quality metrics can be important tools in persuading stakeholders that ongoing co-production efforts are worthwhile. Monitoring the impact of co-production and nourishing sustainable co-production initiatives, however, will require persistence and creativity. By creating new opportunities for clinicians and patients to work together and by providing incentives for clinicians, patients, systems, and payers, meaningful collaboration in system redesign can result in improved health outcomes and proceed in a truly patient-centered manner.

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