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Commentary

Healthcare utopia or dystopia: empowering improved self-management may be a better role for technology

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DAVE'S STORY

The Autumn edition of BCS's magazine for the IT professional, ITNOW,¹ included a health anecdote as part of its Making IT Good for Society theme. The story (Box 1) was about Dave and his health.

Technology to deliver this care is available now

The technological elements Dave needs are available now. Fitness trackers are common place to the extent that UK consumer association Which?² has undertaken a review of over 40 devices. Domestic installations have controllers, such as Nest, which call its third generation thermostat a 'Learning thermostat', which learns domestic routines, knowing when to adjust the heating and what temperature you like. It already has an app to control it, which tracks data about usage, and can also connect to fitness trackers. It would be a simple technological task to develop the linkages and algorithms necessary to do the tracking the story envisages.

The UK National Health Service (NHS) has much of the technology necessary to deliver their part of the story. General practitioners (GPs) have excellent IT systems with the capability to share information, and electronic transfer of prescriptions is common place. According to NHS Digital³ by December 2016, 86.9% of GP practices in England and 99.2% of pharmacies had gone live with the Electronic Prescription Service, capable of sending prescription orders to any pharmacy. Decision support systems are widely used in health, albeit not in the way the story envisages.

The health care system, not the technology is the problem

The health care system necessary to enable the story is perhaps harder to envisage than the technology. GPs are already under pressure dealing with their current workloads, which the King's Fund⁴ has identified as having grown enormously not only in volume but also in complexity. How the service could be developed to manage incoming alerts from trackers from all their patients would need a major rethink about how GP services are delivered.

It could be argued that the early detection of potential problems has the potential to lead to a reduction in demand. It could also however lead to GPs having to manage an ever increasing workload as they have to incorporate responding to the information streams uploaded from patients' home doctor systems, and calling them to arrange appointments or referring them to alternative GPs. It has been found that information alone does not lead to an improvement in care. A study⁵ looking at how the use of an electronic health record (EHR) affected the quality of care for patients with diabetes found that EHR use did not improve the clinical quality of diabetic care.

Box 1 Dave's anticipatory care

Dave finished his coffee and, as he did each morning, he slipped on his fitness tracker, weighted himself and took his blood pressure. The data gathered by all those Internet of Things devices were passed to his doctor.

As he packed (to leave for a conference in London), Dave felt cold. He turned up the heating, and again, the internet enabled thermostat reported to the healthcare computers.

Dave jumped into his car and set off for London. As his car pulled onto the motorway, his family physician/general practitioner (GP) arrived for work. The doctor had received a report by email; Dave Babbage's blood pressure was up; his daily activity had dropped markedly; his temperature was up; and his weight had been trending differently too.

The GP pulled up Dave's records and looked at Dave's heart rate, both real time and historic, there was a problem. The GPs experience and the surgery's AI-based augmentation systems agreed.

The GP could see that Dave was close to London. An appointment was made for Dave to see a GP close to his hotel and all of Dave's medical records and data were made available to the new medic. The new GP gave Dave a checkup and provided him with a prescription. The doctor also provided some lifestyle advice. The medicine would be delivered to Dave's hotel.

Should we be empowering self-management?

The major problem I have with this brave new world is that in spite of the amount of health data generated by a person they are removed from their own health. Dave routinely records activity, blood pressure and weight but is oblivious to the changes. He plays with the house thermostat without noticing how he is feeling. Rather than using all this information to empower Dave to better manage his own health, the system is disempowering him. He is relying on the system to monitor his health without being aware of his own body. The system passes the information straight to the doctor who makes an appointment for him to be seen.

Activated patients who self-manage or adopting a passive sickness role?

Dave is OK, but lost somewhere in between two health paradigms.

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One model is the traditional medical model of healthcare and the 'sickness role' proposed by Parsons⁶ in the 1950s where people were expected to place themselves in the care of medical experts who would apply their medical knowledge to cure the patient. In this story, Dave takes all the right measurements and they are automatically passed to the healthcare computers that analyses the data and presents the doctor with a diagnosis and treatment plan, which the doctor using his expertise concurs with and actions. Dave keeps the appointment made for him and receives the medicine deemed necessary.

The other model is very current model of consumer personalised medicine. This is described⁷ as a patient driven health model, with an 'increased level of information flow, transparency, customization, collaboration and patient choice and responsibility-taking'. Dave meets the first element of this model, which is of information flow, but not the others. He is an active self-tracker, using a range of technology to live a quantified life but remains unaware of his own body and health.

While the discussion is focused on the developing technology, we are neglecting the discussion about how we want that technology to support our individual health and our healthcare systems.

Is this technological utopia actually dystopia?

Is utopia actually taking Dave's story further? Giving all responsibility over to artificial intelligence (AI) systems, using big data to create algorithms that prescribe courses of treatment for 'routine' health problems, freeing our highly qualified healthcare professionals to deal with complex cases and those where a 'human touch' is needed?

Is utopia Dave using the information from his various tracking devices to learn more about his own body and his own health? Getting feedback from his personal AI-based health coach, supporting him being more able to identify how his actions affect his body and recommending when he needs to see a healthcare professional, empowering him with information to facilitate a collaborative meeting?

Or is utopia somewhere else?