Is Expertise Needed? The Practical Implications of a Flood of Health Data

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by

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On my honor as a University student, I have neither given nor received unauthorized aid on this assignment as defined by the Honor Guidelines for Thesis-Related Assignments.

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Historically, patients have deferred to a doctor's judgment. However, wearables, which have proliferated recently (Livingston, 2019), can monitor the wearer's activity throughout the day, providing data that once required special medical devices and a visit to a health expert. To sell wearables, manufacturers claim that they will make users more health-conscious (Fitbit, n.d.). Apple even calls its Apple Watch "the ultimate device for a healthy life" (Apple, n.d.). However, these claims have not been substantiated. What is clear is that wearables are changing the quality of care patients are receiving. The explosion of data has increased health literacy and can help individuals better care for their own healthy. They may make routine checkups unnecessary: "if you're healthy, there's every reason to believe these visits make no difference" Dr. Ezekiel Emanuel contends (Heid, 2018). According to Krogsbøll (2012), Medical checkups are too infrequent for those who are sick. With health data from wearables, wearers can develop training plans or detect early symptoms, thereby promoting health and saving money (Sortsø, 2018). Britain's NHS and insurance companies are evaluating and subsidizing wearables to promote health consciousness and reduce long-term insurance costs (Best, 2018). Wearable data also can help doctors make quicker, better judgements. Despite these advantages, wearables can cause tension between experts and their clients when self-diagnosis from wearable data incurs the hazards of misdiagnosis and distrust. Experts warn that wearers may ignore professional advice and take health into their own, untrained hands (Felde, 2019). A deteriorated doctorpatients relationship lacks trust, and trust can substantially enhance a physician's ability to heal

and provide comfort (Pellegrini, 2017). Only when people are educated on both the benefits and the limits of wearable data can they maximize the benefits wearables bring.

Review of Literature

Haghi (2017) contends that "sensors have made investigation of a full range of parameters closer to realization." Dias and Cunha (2018) find that researchers can use data from wearables to investigate rare diseases. Metcalf (2016) finds that wearables can provide vital signs during transport to hospitals and in operating rooms.

Researchers have studied perceptions of wearables. Project Catalyst (2016) researchers found that users want to know their daily activity levels. Gualtieri (2016) found that to users with pre-existing medical conditions, wearables increase self-efficacy. Piwek (2016) found that continuous use improves wearers' health. Nevertheless, according to Asimakopoulos (2017), "even the most popular trackers see a drop-off rate of 50% within 2 weeks of use."

Wearables are cost-effective. Arentz (2016) reports that wearables can economically promote specific behavior. Sortsø (2018) confirms that wearables can reduce long-term medical costs.

Researchers have studied wearables' disadvantages. According to Gabriels (2018), some doctors are troubled by patients' management of their own health. Knowles (2018) reports that some users treat health data as a substitute for professional advice.

Xie (2018) found that wearables had "high measurement accuracy with respect to heart rate, number of steps, distance, and sleep duration" but poor accuracy during physical exertion. Nelson and Allen (2019) found that the "golden standard" for wearables had "a mean absolute error percent of 5.86%, and a mean agreement of 95% when compared with the ECG across 24

hours." Manso (2018) found that other wearables such as the Samsung Gear S3, and similar types "of commercial wearables, are not yet fit for long term monitoring to be used by physicians in either diagnostics nor patient follow up."

Good doctor-patient relationships are critical. Goold and Lipkin (1999) calls the relationship a "keystone of care" as it "directly determines the quality and completeness of information elicited and understood." Ha (2010) contends that patients are now "actively reconstructing expert information to assert their own perspectives," sometimes to the detriment of their health. Kaba and Sooriakumaran (2006) found that the doctor-patient relationship is transforming from paternalistic model to a more patient-centered model with reduced physician dominance. Goold (2002) finds that without trust, a physician cannot expect patients to reveal the full extent of their medical history, expose themselves to exams, and act on recommendations. Birkhäuer (2017) found "moderate correlation between trust and health outcomes."

Wearables Promote a Healthy Lifestyle

Wearables promote self-efficacy by providing information wearers need to make healthy decisions. Jess Eddy (2018) proposes four strategic pillars of a successful fitness routine, including accountability and monitoring, where wearables can make the biggest impact. According to Project Catalyst (2016), "trackers increased awareness [and] motivation." As one study participant said, "at the end of the day I can look at my activity tracker, and if it's low I can go for a walk." Wearables let their wearers monitor their activity and adjust it as needed. Collier (2019) writes that "although I'd previously tried to make lifestyle changes, I wasn't consistent — or patient. Failing to see results quickly, I wouldn't know if my actions were doing any good. I'd get discouraged." Being able to monitor her progress kept her motivated and she saw weight loss

of 10 pounds in 30 days. Health trainers like Steven Dieltz support the adoption of wearables because people striving to improve their fitness need "a slow progression... staying consistent." A heart rate monitor can help them pace their progress accordingly (Kollmorgen, 2019). Some doctors such as JoAnn Manson even consider exercise an "additional vital sign" in addition to the classic four (Kuchler, 2019). Wearables can go beyond providing motivation and even prevent injury. Pete McCall, a health and fitness expert, says that a heart rate monitor can help you determine the correct intensity of your exercise, reducing overtraining, which "increases your chance for injury and can hinder your day-to-day performance, and it puts a ton of stress on the body" (Tucker, 2016). One person on Reddit complained that he has "major pain in my knees, my abdomen (left side), and my hips" (MrShizzBear, 2015) after running 10 kilometers blindly. Reimut Hellmerichs says that he wants to "enable athletes to train proactively... by identifying activities that increase different load parameters" (Roth, 2019).

Wearables can track more than heart rate and are starting to be widely used by diabetics. The information gathered is valuable "as it distinguishes momentary anomalies in blood sugar spikes from true, long term patterns" (Balasubramanian, 2020). Users like Henrick Berggren (2018) found that wearables allowed him to track is blood sugar level much more easily. One of his three main advantages was that there was "no more pricking your finger several times a day with bulky equipment." Wearables can also enable virtual doctor visits saving time (Jones, n.d.). Dr. Tyrone Krause says that while wearables aren't a substitute for regular monitoring by a doctor, it can "still give you a better idea of what's going on… even if it's not 100% accurate." Insurance companies like UnitedHealthcare seem to support this notion as they will reward users up to \$1500 a year for wearing a Fitbit device and for reaching daily fitness goals (Gurdus, 2017). Some companies such as Wechat (2017) have capitalized on this, allowing wearers to

engage in friendly competition, further promoting accountability. Dianna says that "Competing with friends is so much fun! It's addictive" (StepUp, n.d.).

Wearables are not pills taken to relieve an ailment. According to Jo (2019), "wearable devices play a role as a facilitator in motivating and accelerating physical activity." While they can put wearers on the right path and help them monitor their health, ultimately the wearer is responsible for extracting the benefits.

An Evolution - Not the Revolution Manufacturers Promise

"Big tech companies, small tech companies — everyone seems to be getting into the market,' says Thomas Rieck, a wellness and exercise specialist for the Mayo Clinic" (Collier, 2019). According to Professor Jordan Etkin, "people are really curious to know more about themselves" (Volpe, 2019). This void means tech companies are all vying to establish a foothold and garner the most customers.

With the introduction of wearables, manufacturers have promised that wearables will completely change the way users manage their life. "Devices are marketed under the premise that they will help improve general health and fitness, but the majority of manufacturers provide no empirical evidence to support the effectiveness of their products" (Piwek, 2016). Manufacturers claim that they will make users more health-conscious (Fitbit, n.d.). Dr. Darin Morse, however, says that just wearing a device won't do anything by itself, "you actually have to do the work if you want to see results" (Collier, 2019). Apple goes as far as calling its Apple Watch "the ultimate device for a healthy life" (Apple, n.d.). Apple and Fitbit are not the only companies to create wearables and mobile health applications, however, overall "the body of evidence of effectiveness was of very low quality," said Byambasuren (2018).

With the adoption of new technology comes wariness. Over a third of wearers of wearables are concerned with inaccuracy in measurements (Clark, 2019). The fears are not unfounded. There is a class action lawsuit against Fitbit backed by a study claiming that "the results of this investigation demonstrate that the PurePulse technology integrated in Fitbit's heart rate monitoring devices is not a valid method for heart rate measurement, and cannot be used to provide a meaningful estimate of a user's heart rate" (Jo and Dolezal, 2016). It's not only Fitbit, but many other manufacturers as well that do not meet their claims of accuracy according to Profis (2014).

While wearers such as Rainmaker (2016) recognize the inaccuracy in data from wearables and use them only as estimates, those who are not aware could suffer. Collier (2019) wanted to stream all her wearables data directly to her doctor just like she had done with a Holter monitor (portable ECG) years ago. She did not realize the data was unreliable and asked her physician to make health decisions based upon the readings. She was informed by her physician that some devices are meant to be used medically while others were not. There are many other users like Collier. LakeDiva (2020) complained on Fitbit forums that "I will meet my exercise goal for 7 days in a given week and it will show 3 of 5 days, last week I had a day where it showed I climbed 30 flights of stairs when I might have climbed 1 and did not walk on a high incline." Only then did others inform her that this does occur with varying frequency, with another user, Heiliskiak (2020), lamenting that "it's too expensive to just be a curiosity." In a different forum, Mada82 (2017) wondered if the device was faulty when it registered 159 steps in the shower and 200 steps in the bedroom.

The future does hold promise. Valencell, a producer of biometric sensors, like many other manufacturers have realized that accuracy is a top priority through a survey in 2016. In the past 3

years, Valencell has published at least 20 press releases dedicated to the accuracy of their products or the importance of accurate data (Valencell, n.d.).

Wearables Help Doctors Save Lives

Personal wearables are granting doctors and researchers a better insight into how the human body works. As professor Jacek Urbanek said, "people can overestimate on surveys how much and when they move, but wearable devices provide accurate data that cuts through bias and guesswork." Another professor, Ekaterina Smirnova commented that "a simple summary of measures of activity derived from a hip-worn accelerometer over a week outperformed wellestablished mortality risk factors such as age, cancer, diabetes and smoking" (McGrail, 2019). In addition to researchers of rare diseases, doctors conducting clinical trials use wearables because with them "we are not only making advances in scientific progress and innovation, we are creating novel opportunities within the rapidly changing clinical trial landscape to capture the complete patient experience" (Pfizer, 2019). Dr. Dush Gunasekera believes that "the more accurate data we have on our patients, the better we can help with their health problems. Sometimes a snapshot can be just enough to give us the indications of a problem, or to prevent us missing one" (Heubl, 2014). Others, such as Dr. Ida Sim, see little benefit: "if you told a doctor, "We can run chemistry and liver panels on your patients every day for the rest of their lives... they would look at you like your crazy" (Sukel, 2019). It is clear, however, that wearables give doctors a new tool.

While many benefits of wearables come from the ability to monitor long-term data, wearables can help doctors in emergencies. Fitbit data have helped doctors determine how long a patient's heart had been racing. In another case, a Fitbit advised an individual to see a doctor,

who diagnosed organ failure (Marshall, 2018). Bonnie Spring, a professor of Preventative Medicine said that "this is fairly cutting-edge, because we are capitalizing on the fact that people don't need our help all of the time — they just need it when they are at risk. The problem is, they don't know when that is, and neither do we" (Plumridge, 2017). Jason Perlow (2018) claims that "I owe my life to my Apple Watch," which caught atrial fibrillation, a condition often gone undetected and can be fatal. Jason Zagrodzky, a cardiac surgeon, routinely treats patients that were alerted to problems by their Apple Watch and "would say probably at least once or twice a week someone comes to me solely because their watch said, hey, you've got a serious problem" (Holmes, 2019b). Wearables also help those who are incapacitated. Gabe Burdett credits the Apple Watch for saving his father's life by automatically calling 911 after his father was knocked unconscious falling from a bike (Brito, 2019). James Prudenciano also claims his Apple Watch saved his life, after he fell from a cliff and fractured his back in three places (Holmes, 2019a).

Doctors can also monitor themselves. The Surgical Metrics Projects by the American College of Surgeons (n.d.) explores "the use of wearable technologies to measure surgical decision making and surgical technique." Wearables can improve a surgeon's technique. Carla Pugh says that "In the field of surgery, there are no metrics to back up what it is that we do, or the range of tactics we employ to get positive surgical outcomes" (Armitage, 2019). "We walk around with more detailed data about our bank accounts than how we perform clinical procedures, which are 10-times more complex." Wearables change this.

Wearable Data and the False Sense of Knowledge

Data is instrumental in making the best decisions, but often overlooked is the expertise

needed to accurate make sense of information. In the case of medication, this is clear says Arun Jayaraman, "monitoring allows clinicians to know what happens when a patient gets a medication or goes to physical therapy." However, not all patients realize their doctors do more than simply look at the data. "There is a lot of over- or under-prediction of performance in devices such as Fitbits, and for the average person, an approximate calculation is okay, but for patients where physicians may want to change a drug dosage, therapy plan or gauge whether surgery is needed, it's important to have accurate and precise data" (Plumridge, 2017). Collier (2019) thought that "With the right device, you can easily measure your heart rate, blood pressure and more. Maybe if I loaded up with all this new technology, I could get a handle on my health." She "was surprised — and disappointed" at the truth.

Wearables can also compete with professional advice. According to Landi (2019), individuals are more willing to adopt wearables if they can save them doctor visits. When someone self-diagnoses, they may neglect the implications of the diagnosis (Pillay, 2010). With more information, patients may be more likely to go to a professional with conclusions instead of symptoms (Godman, 2018). This is worsened by the rise of the internet. As Rhonda Frevert (2019) said, "a site I turn to first with medical questions is MedlinePlus at medlineplus.gov." Many medical professionals warn that self-diagnosis from wearables can be dangerously inaccurate (Banks, 2019). According to one doctor, self-diagnosis can "miss a medical disease that masquerades as a psychiatric syndrome." The patient may "think there is more wrong... than there actually is." Constant monitoring can cause overreactions to minor symptoms, such as a racing heart due to stress or too much coffee (McGrath, 2019). Carpenter (2010), a self-described hypochondriac had "hours were lost on the internet" searching up medical conditions that might align with her symptoms.

Self-diagnosis "undermines the role of the doctor" (Pillay, 2010). It causes conflict with the doctor and deteriorates the doctor-patient relationship. According to Ingrid Pipes, an individual with a chronic thyroid condition which affects weight, "doctors have refused to prescribe me the medication for my thyroid unless I lose weight, even though if my thyroid was working properly, I would lose weight." Pipes asserts that her "numbers have never been 'off'" but "doctors tend to see fatness before they listen." Pipes therefore ignored professional advice (Keppler, 2018). According to another doctor, Bryan Vartabedian, "I was the arbiter of information in the 1980s and 1990s, but in the first decade the internet was around, patients were coming in challenging me with things they had found" (Zocdoc, 2018). Another doctor commented: "I had a patient who said he has brain tumor. When I asked how he got to know, he said the internet told him so when he Googled his symptoms. I was speechless" (Hughes, 2019). The result is a hugely degraded doctor-patient relationship.

Doctor-patient relationships are key to ensuring best treatment. "Patients who trust their doctors are more likely to follow treatment plans" and "trust is one of the best predictors of whether patients follow a doctor's advice" (Khullar, 2018). Harold Sherrell skipped a trip to the doctor's office once and regrets it: "Ten years on, my finger is crooked. I think it's a boneheaded move for me not to [go see a doctor]" (Keppler, 2018). According to Dr. Armen Henderson (2019), he had a patient who's lack of trust was so severe that "he'd never accept chemotherapy from any doctor — even if it could have cured his disease." Thom (2004) also says that trust is linked to greater treatment adherence, more continuity in providers, and greater patient satisfaction.

Conclusion

The rise of health wearables was inevitable. Biometric sensors that were once reserved for expensive, specialized medical devices are now small and cheap enough to be embedded into watches, illustrating the validity of Jevon's paradox once again. From automatically calling emergency services to evaluating the actions of a surgeon in the operating room, as wearable technology proliferates, people and groups find more ways to use it.

While wearable technology can help people be healthier, it is not a pill for an ill. At the end of the day it is merely a tool that people use, just like food triangles, food labels, or exercise recommendations. Wearable data, like all other quantitative metrics facilitate goal making and promote accountability.

It's not a surprise that every manufacturer is racing to introduce their wearable. A new field brings opportunity. What should be examined is the balance between interests, ideas, and values. Over-promising capabilities might create short term monetary benefits but harms users and creates distrust. Just as bad is under-informing users of what a product does is just as bad. Letting non-experts infer from their own experiences of what a technical product does can lead to dangerous misconceptions and undiscovered knowledge gaps.

The change in the doctor-patient relationship from being paternalistic to one of a partnership begun long before the introduction of wearables. As people have more access to knowledge, they are able to formulate their own opinions instead defaulting to an expert. The flood of data from wearables creates conflict as differing opinions clash. Wearers can easily access health data, but this does not equip them to interpret the data. This skill demands expertise. Thorough discussion and examination of ideas lead to better outcomes, but the prerequisite is a foundation built upon knowledge and facts.

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