HEALTHCARE INFORMATION SYSTEMS USERS

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Abstract

The user in this paper is not a medical specialist, but a real user of healthcare, a patient. The first author's personal experiences as a Parkinson's Disease patient for over 12 years form the basis for concerns that need to be addressed if Healthcare Information Systems are to succeed. Seven short stories are told as the basis for supporting this user's perspective of these concerns. In particular, the theme of the paper is that ignoring the patient cannot lead to Information Systems success.

Keywords: Healthcare, Information Systems, electronic patient-centric records

1   Introduction

This paper is a shorter version of a paper by the same authors that has been submitted to the *Journal of Health Systems* (Paul et al, 2012)

There are three kinds of people who work/exist in healthcare. The first kind are the medical experts and medical support staff (doctors, nurses, ambulance staff, phlebotomists etc); the second kind are those people who support the first kind (administrators, cleaners, porters, computer experts etc); and the third kind are patients. When talking about Information Systems in an organisation, a user is normally someone who uses the system on behalf of the organisation, a provider, which in healthcare is one of the first two kinds. But in this paper we are going to look upon the user as the patient, the inevitable user of healthcare as a system, and therefore on the receiving end of any Information Systems the first two kinds use. The providers tend to determine the information systems used in Healthcare because they have the power to do so, controlling budgets and generally being more permanent fixtures in the system.

The purpose of this paper is to suggest, through a user's perspective, some of the important concerns that need to be taken into account in order to successfully use information systems in healthcare. To avoid confusion over the use of the word user,

we shall distinguish patients from the normal use of the word user, by calling the former 'patient-users'. This also aptly describes one of the major requirements of any patient-user, namely patience.

Section 2 draws some tentative conclusions from the literature about the reasons for those disappointments. Section 3 introduces a patient-user perspective of the concerns that must be taken into account for Healthcare Information Systems success. Sections 4 and 5 discuss seven stories that the first author (who has Parkinson's Disease - PD) presents in support of these concerns. There is no intention to declare a definitive or prescriptive list of reasons for Information Systems disappointments, merely to show that a patient-user perspective can highlight some of the concerns worthy of debate. The last section draws conclusions

2   Why is I.S. in Healthcare Difficult: First, Do Less Harm

The sub-title of this section is the beginning of the title of a book called "First, Do Less Harm: Confronting the Issues of Patient Safety" by Gordon and Koppel (2012). Chapter 4 by Koppel et al (2012) is called "Health Care Information Technology to the Rescue", and is a very readable presentation of lots of good ideas, and the things that have gone wrong with them (Decision Support Systems, Expert Systems, EPR systems etc). The authors take the reader on a journey of revelatory discovery as system after system is found wanting in a variety of obvious ways (obvious when you know of course). The chapter is so well written that we recommend that any reader of this paper should go and read the original chapter rather than seek an impoverished version from us,.

The chapter ends with a section on "What To Do? Specifics", all of which are worthy things to do in their own right. But surprisingly, no mention of the patient-user!

3   A patient-user perspective

The patient-user perspective presented here is based on the experiences of the first author, who has been working as an Information Systems academic for 25 years, and who has been a PD patient for the latter half of this time. What is offered here are

some major concerns that do not appear to be well thought-out in the literature properly if at all, but in the view of this patient-user, have an important impact on the development of any healthcare Information System. Some of the concerns arising from this patient-user perspective have the potential to negate all the benefits of an Information System based on the literature.

An attempt to highlight the relationships between these concerns failed when it was realised that all considerations were related to 4 to 6 of the other 6, which made a diagram rather superfluous, but does show the complexity of the problem

First: The doctor patient relationship and fear. The relationship between a doctor and a patient is very different to that of a customer supplier relationship. Apart from a formal lack of profit motive (of the system at least) if things do not work out, the patient could, in the worst case, die. So it is not surprising that many such doctor patient relationships are enmeshed in fear, at least on the patient's side. The call for a patient centric system is admirable, but one has to remember that the relationship is a function of the patient's ability to articulate the symptoms, and of the doctor to extract them from the patient. It will always be true be that more articulate patients are likely to receive better treatment because of their quality involvement in the process. Most medical diagnoses are largely based on what the patient tells the doctor, so a poor 'bedside manner' in combination with a patient who cannot express her/him self well is unlikely to benefit much from any kind of Information System (including artificial intelligence). In fact, if the patient-user searches the web and diagnoses her/him self, the relationship is off to a flying start.

Second: Patient or physician centric EPR. Whilst the literature gives the highest priority to having electronic record systems, and that these should be patient centric, it is hardly surprising that there is a lot of difficulty in developing such a system. Clearly, transferring the contents of a paper record to an EPR system will not suffice in future additions to the system if the system is to be used for patient centric purposes, because physician centric systems do not collect all the data needed to look at patients. Worse than that, it is doubtful anyone can answer the question, what data should be collected in a patient centric system? In a physician centric system, the data is collected for the physician's own needs, and a reasonable guess at what this might be can be considered by the physician. But in a patient centric system, in order to reap all the potential benefits, the data required by the healthcare community at large would need recording in some meaningful way - and who knows what that is!

Third: There are no healthcare savings. There is no limit to the amount of money that can be spent, especially in a climate of rapid acquisition of new and better cures, medical techniques, operating practice etc. A healthcare system cannot generate 'savings'' in its operations. Any attempt to do this is just another way of cutting the budget. 'Savings' can always be readily spent on any one of many worthy medical activities. You may be able to improve the healthcare provision within a budget, but how would you measure this? We shall discuss quality control below in number 6. Suffice to say if you could measure the quality of healthcare, this might lead to a league table of quality of life medical practices, which could be taken to imply that only the top X practices should be funded, obviously a nonsense.

Fourth: Healthcare is naturally subject to change. There are medical advances, fashions in treatment, fringe medicine that comes and goes, much learning from different cultures etc. In a static age of medical discovery, it may be possible to take a steady state analysis of the healthcare systems and the demands on them, and try and make them more effective using optimisation techniques or other system 'betterment' approaches. But given the speed of current medical discovery, the search for stable systems that can be made more cost effective is a waste of time. Medical discovery is not at a constant rate either, so even if methods of dealing with systems that exhibit constant change behaviour were to exist, these methods would not work for healthcare either.

We shall see in the next section some examples of medical change that make all the paraphernalia of the Management Sciences ill-equipped to deal with healthcare systems.

Fifth: Longevity of patients. Healthcare is for life, a somewhat unusual length of time for a relationship outside healthcare. How many organizations work with the same human being for as long as 70 years? What will healthcare be like in 70 years time for today's newborn baby? What will anything be like?

Sixth: Quality control? Many social, economic, political systems have some form of quality control associated with them (for which the first author has to make the comment that they are largely bunk). But what is quality control in healthcare? 'Take 20 patients with a heart problem, carry out necessary heart bypass surgery, and if they all live 50 years', that's quality etc (it would take a long time to find out).

Seventh: Death is healthcare failure. Death is guaranteed, so Healthcare must eventually 'fail'.

4   Stories

Having stated the concerns that need to be addressed when looking at Healthcare Information Systems, this section checks them out against seven stories from the patient-users' experiences. The following stories could be exalted by calling them case studies, but such use of labels makes no difference to the message of this paper. The stories of a patient-user are given in the first person since they are so particular and personal. Much of this material has been presented in Paul (2009), an autobiographical account of a PD patient, told with black humour to make it more palatable.

`**Story 1 PD Diagnosis:** I was officially diagnosed with Parkinson's Disease in February 2000, having diagnosed myself in late December 1999. On reflection, my health throughout 1999 was not good, but I put this down to being out of condition because my job was so demanding. There had been warnings. I went to a gym to exercise in Spring 1999, and the person showing me how to use the machines observed that I had a lazy left leg. On holiday that summer, after a scare resulting from what seemed to me to be the possibility of my drowning, I collapsed and found my way with difficulty to a health station. There I was put on a saline drip, and told to have my 'lights' checked when I returned to the U.K

After a plethora of checks, my doctor diagnosed a 'funny turn'! I asked my PD consultant about this sometime later, and he made the point that PD is difficult to diagnose. I had done some reading, and checked with him whether it was true that my life expectancy at that point was 8 to 10 years. He cheered me up by saying that the book I had looked at was out of date, three had been significant advances in medication, and that a better estimate would be a reduction in life expectancy of around two years. As I left my consultant my happiness was somewhat reduced when I realised that this estimate meant absolutely nothing to me the individual – it might be of some use to an actuary.

Table 1 shows the outcomes of considering each story against the concerns from a patient-user perspective of developing I.S., for Healthcare. The text associated with each story gives a fuller picture. So, the seven concerns are as follows for story1:

The patient doctor relationship was excellent, the treatment and advice first class. But I was still in fear. The record keeping appeared to be both physician and patient centric, that is, records were kept for both interests (see story 2 below for example). There was no indication that my treatment was in any way limited by resource constraints. Change was endemic, medicine came and went. My longevity was apparently reduced by 2 years. There was no observable quality control, other than that I slowly got the symptoms under control with medication - but this was hardly surprising since patients tend to have different experiences one from another, suggesting that PD is a family of diseases rather than just the one common disease. Obviously the treatment is working at the moment (I am not dead) so for me it is successful so far. This last result is true for all hr stories, and so it will not be repeated in the remaining stories.

Story 2 Parallel Illnesses: My consultant behaves as though my PD will be the cause of my death in the end, and anything else that comes along must not get in the way. He quickly gets whatever it is sorted out (with the support of my doctor who happily agrees to what he proposes, but does not have to). So in the early days, for example, I went to a deep vein thrombosis (DVT) outpatient clinic for a check up. On arrival the receptionist asked me "Heart or Leg", and my answer of 'leg' assigned me to second class speed of service; 'hearts' were the priority. After a long wait I went into an open plan office space where I met a doctor who had obviously been working non-stop for days, and a very pleasant student doctor. The worn out doctor kept coming in and out, mumbling about finding this or that form. After about half an hour, the Registrar joined us, casually ignored the doctor, checked out my legs, told me they needed exercise and inferred that his time was being wasted. The seven concerns are as follows for this story:

The patient doctor relationship was satisfactory, but I was in fear until I was informed that all I needed to do was exercise. Record keeping as I observed it seemed physician centric, but not patient. I was not aware of any resource constraints other than the junior doctor's exhaustion. The latter could be taken as a way of getting more work from the junior doctor, but the quality would be so poor, it could not be effective. I saw it more as a route of passage. I was not in long enough in this particular part of the system to observe change. What I had experienced had no discernible effect my longevity. I observed no quality control, especially with the junior doctor.

Story Concern	Diagnosis	Parallel illness	Bike riding	Stress	Side Effects	Thanks but	Double DBS
Patient-doctor & fear	Yes Yes	Yes Yes	No Yes	No Yes	Variable Yes, yes	Yes Yes	Yes Terrified
Physician/ patient centric	Yes Yes	Yes No	Yes No	Yes No	Yes No, a bit	Yes Yes	Yes Yes
Resource limited	No for me	No	No	No	No	Yes relief	Yes
Change	Yes All the time	N/A	N/A	Yes New	Variable	Yes New	Clinical Trial
Patient longevity	Yes -2 years	No	Yes 0	Yes 0	Variable	Variable	No one dead yet
Quality control	No	No	heart attack	No '1 to 10'	Not much	No	Number 6
Death or success so far	No Yes	No Yes	No Yes	No Yes	No Yes	No Yes	No Yes

Table 1. **Table showing how the Stories fit against the Patient-user Concerns.**

Story 3 As Easy as Riding a Bike: In 2005 I mentioned to my consultant that I had chest pains sometimes. I found myself in the Rapid Access Chest Pain Clinic. The activities that occur there bear some extensive telling, since I found them to be a typical example of common happenings. On arrival I was asked to fill in a form. I don't know why, because every question on the form was asked of me verbally later, often more than once. In this process I became Paul Raymond. Nearly all hospital forms ask you for your name in reverse order, family name then given name. Many people think I have filled in the form the wrong way round and it took 30 minutes for me to get my name back. Then on to the bicycle test, where I was asked, along with many questions from the form, when I felt the chest pains since they wanted to recreate the conditions. I said to do that I would need a large meal, two glasses of red

wine, and a slight incline/hill to walk up. The nurse was nonplussed and suggested I went to see the consultant without the test first. The consultant told me he thought I needed an endoscopy or some such, and some other rather evil sounding things. But he wanted me to do the bike test. Back to the nurse and the bike. She wanted me to fill in a disclaimer form, and told me why when I asked her. I put it to her that I was in the clinic because there was a possibility I was heading for a heart attack, and there was a 1 in 10000 chance (or whatever) that riding the bike would give me one. I was asked if I wanted a copy of the disclaimer form, to which I observed that if I died I could not see that I would have any use for it, and if I didn't die, I would certainly would not need it.

I passed the bike test with flying colours, a probability of a heart attack around the level of all males in the population, far better than my age group. The consultant decided not to do the endoscopy, but he would prescribe some medicine for me. The first was a beta blocker to keep the heart nice and calm. The trouble is as a Parkinsonist, I need speeding up not slowing down, so they were quickly jettisoned. The second was a spray, which I understood works as follows. If I felt the chest pain, then spray under my tongue. If the pain persists spray it again. If it still persists, spray once more. And if it still persists, - well, you are dead! Comforted by such imagery, I was really cheered up when the pharmacy told me that if I use the spray it would give me a headache. The seven concerns are as follows for this story:

The patient doctor relationship scarcely existed, the doctor was so keen to diagnose without much evidence. Clearly I was in fear, heart attacks can kill. Record keeping was entirely physician oriented. There were no discernible resource constraints. My longevity was an issue, I could be dead at any moment! Quality control seemed largely to be a function of percentage of patients who have heart attacks.

Story 4 Stress and Pain: But I wasn't quite free. A stress echocardiogram was ordered, and eventually (for reasons described in my book, Paul 2009) I took the test. A normal echocardiogram was first, to benchmark the data, and then chemical was introduced that made the blood system work harder. When things were quite difficult I was asked on a scale of 1 to 10 where I was. I said eight, but I should have said 11, because more chemical was introduced and I really felt it. When the test was complete I asked the equipment operators if they had ever tried the test for themselves, and they replied negatively because the test was 'far too invasive'. I quite

agree. I returned a week later to get the official result, and the clinic head congratulated me on two pieces of good news. Two? I asked what they were and he replied that was my heart was essentially sound, and that I was cured of PD! I informed him that there was no cure for PD and he seemed surprised. So much for total medicine. The seven concerns are as follows for this story:

The doctor patient relationship was friendly at the human level, but professionally poor. Fear got worse and I was glad to be out of there. Record keeping was entirely for the physician? There were no obvious resources constraints and this was a newish procedure that was changing with use. Again, as in the previous story, heart stories can be quite short. The quality control questions are answered by the question I was asked of where on a scale of 1 to 10 are you?

Story 5 Side Effects Can Kill: In 2008, the PD medication I was taking was found to have caused me a lot of damage. Starting with a blood test at my doctor's, which showed my haemoglobin count approaching half of the recommended levels, I found myself over the next six months visiting an outpatient clinic of one sort or the other weekly. I visited the Gastrointestinal Surgery, the National Pulmonary Hypertension Service, Respiratory, Cardiology, Haematology, Clinical Neurophysiology, the Neuromuscular Unit and probably one or twoI have forgotten. There were some delays in getting entry to the system, which was resolved by an arrangement with Accident and Emergency that I should be a walk in patient and take it from there. I was visited by the A&E Registrar who queried this irregularity until informed by his colleagues that they had arranged it. The Registrar was not amused, but when the results of some tests came in, he became more sympathetic and added to the tests required once he saw the appalling data. The seven concerns are as follows for this story:

The patient doctor relationship was extremely variable, off-hand at one level to extremely supportive, interested, and willing to dirty hands for me. Most encounters generated fear in me. Whether it was heart or blood or lungs or whatever, none of these seemed good news to me. There was little evidence of collaborating between specialities (only two specialities had a joint meeting to my knowledge).The patient recording systems being used were largely physician centric with little evidence of patient centric data. There was no evidence of the treatment being restricted by resource issues. Evidence of change was a bit variable as was the

potential effect on longevity. There was not much discernible evidence of quality control.

Story 6 Thanks But No Thanks: As diagnosis and treatment took off apace, the change of PD medication started to have effect, and slowly my body returned to its usual state. One by one the clinics discharged me. In this process, I was booked into hospital for a week with the National Pulmonary Hypertension Service for a series of tests, culminating in micro cameras being inserted through sensitive parts of my anatomy to look around. The tests went well, and by the Wednesday it became quite apparent that the symptoms were much improved. A huddle of doctors appeared in the ward, whispering to each other and sneaking looks at me. I guessed what the problem was and when they ventured over, I started the conversation with the suggestion that since the tests had gone so well, did we need the camera work? The sense of relief could be gauged by the worried expressions turning into smiles and after one more straightforward test, I went home. The seven concerns are as follows for this story:

The patient doctor relationship was very good although fear, because it was the heart, was ever present. Recording data appeared to be both physician and patient centric. Evidence of resource constraints might explain the relief of the doctors at not having to do the extensive planned testing. Evidence of change lay in the fact that the whole approach was new. My longevity was a function of my heart with a variable possible number of outcomes. There was no evidence of quality control.

Story 7 Double Deep Brain Stimulation (DB): From 2009 my PD got worse, and I started falling over, so much so that 2 years later I was falling over 50 times a month. Although most falls I could anticipate and 'roll' into them to minimise damage, it was obvious that if I did not find a way out, I would eventually break something, which because of PD, would make recovery extremely difficult. My consultant had mentioned a clinical trial he was part of, essentially a double Deep Brain Stimulation (DBS) operation. DBS operations are now quite common, but the clinical trial operation implants four electrodes in pairs into different parts of the brain to influence the symptoms of PD and also to affect balance. In late 2010 I agreed to consider the operation. It was made clear to me that I could withdraw at any time for reasons that will become apparent. I went through a large number of tests, including psychological and it was confirmed I was a suitable patient. The operation itself costs of the order of $50000 (there were 20 people in the operating theatre) of which: half

was to be met by the company supplying the electrodes, batteries etc (it was in their interests for the clinical trial to be a success); and half from the local area health service where I lived.

The operation was conducted in two parts in June 2011 a week apart, the first to drill the four holes into the brain and implant the electrodes, the second to implant the batteries and connect on the wiring beneath the skin. I was awake throughout the first operation, since to some extent the surgeon is guided by the patient's responses (hence I could withdraw at any time since the idea of an awake bolted down reluctant patient being operated on does not bear thinking about). When I was eventually switched on, the unknown factor was the amount of medicine I now required. The electrodes were set to take up most of the desired benefits, but it is not yet possible to set them accurately enough, and in case, some PD effects are not covered by these electrodes. So some medicine must be taken as well (much less fortunately, which can be shown to more than offset the operation costs). But how much medicine? It took about a week to get to a reasonable level, starting with a dose which in combination with the trauma of the operation left me flying on the ceiling! The seven concerns are as follows for this story:

The patient doctor relationship was excellent, although some members of the research team sometimes forgot we patients are human beings as well as research tools. This story has the same main doctor as story 1. But even so, rather than just fear, I was terrified at the prospect of the holes being drilled whilst awake. Data recording appeared to be both physician and patient centric. This is an obvious example of resource limitations (the local area health service could have said no). The operation was part of a clinical trial, and in itself, and in the trial outcome, is a procedure that inherently changes things. Patient longevity is an unknown, but no trialist is dead yet. I am patient number 6, whatever that says about quality control

5   Summary Discussion:

The table shows that my relationship with doctors is usually good, but fear is ever present. My PD consultant is both physician and patient centric, but most doctors are just physician centric. Two clinics held a joint meeting to discuss my case which shows some patient centricity. I rarely found resource a problem for my treatment,

which I guess says something about the severity of PD. In the Pulmonary Hypertension Unit, relief came from my proposing not to have some expensive tests. Change as far as I could tell varied a lot in kind, from the creation of new clinics, to PD's fast changing medication, and on to brain operations. The effect of any treatment, and the reasons for the treatment, has variable impact on length of life. For my DBS operations, there was a 1 in 2000 chance of death during the operation, a statistic I would not have worried about if there were 2000 of me. But there is only 1 of me. Obviously the death row is negative; else you would not be reading/hearing this paper. So healthcare has not failed me yet. So let us move on to the conclusions to see what has been established?

6   Conclusions

The purpose of writing this paper was to take the first author's kaleidoscope of patient experiences and report back to his professional community the observation that Information Systems are largely undertaken without giving much thought to the patient. In this paper we have shown that ignoring patient-user concerns is likely to leave I.S. in Healthcare as unsuccessful as it currently is. We have shown the patient-user concerns through some real and personal examples of healthcare in action, and these experiences reveal the importance of these concerns in any Healthcare Information Systems Development.

A list of patient-user concerns that influence IS development has been drawn up (to be amended, expanded, improved upon by future research).. This paper shows that when developing IS systems in healthcare, remember to consider these concerns.

7   References

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