Patient Intelligence

Dovepress
open access to scientific and medical research

Open Access Full Text Article

REVIEW

Let's be effective, let the patients talk! Does 'patient intelligence' have an effect on improvements in quality within the healthcare environment?

This article was published in the following Dove Press journal:
Patient Intelligence
27 October 2009
Number of times this article has been viewed

Nadine van Dongen

Van Dongen Research Ltd,
London, UK

Patient Intelligence downloaded from https://www.dovepress.com/
For personal use only.

Abstract: This paper examines the interaction of patients within the context of efficiency in the pharmaceutical environment. Measurements of quality standards in healthcare are reviewed with an emphasis on the question of whether 'patient intelligence' can improve quality standards in healthcare. Something given particular consideration is the ethical point of view versus the business point of view, in relation to the integration of patients into the decision-making process of a healthcare organization. The paper focuses on the formal and informal reasons for involvement of patients in corporate and/or market access strategies for healthcare organizations.

Keywords: healthcare, decision-making process, efficiency, patient intelligence, patients

Introduction

It has been proposed that surveys and interviews can be used to elicit the views patients have on the delivery of healthcare and serve thus as a tool for quality improvement.[1] The views patients have can then be circulated and given to healthcare providers as well as the public in order to highlight areas in need of improvement.[2] Although this opportunity already existed, for many years, and even though it has been available to healthcare professionals and governmental organizations interested in the quality of care management, a large randomized trial ascertained that there was no effect on subsequent patient satisfaction.[3] After another randomized trial in which general practices were allocated to either the intervention or control group, it was concluded, that in the eyes of the general practitioners (GPs), the patient survey took considerable time and energy and GPs found it difficult to use the feedback provided to actually improve their performance.[4] Performance can be viewed in the broadest sense of the word and therefore questions that arise include 1) are the right drugs delivered to the right patients? 2) is the information provided by the healthcare provider sufficient and understandable for the patient? In general, previous research indicates the need to explore how patient surveys and interviews can be used in different ways by professionals who are willing and able to take the time to improve the quality in healthcare.

This article elaborates on the different ways patient feedback can be used in order to improve quality in healthcare. First, I will evaluate the quality standards that have been measured which are currently widely accepted and review their accuracy, then I will elaborate on the patient voice and its implications. Patient intelligence will be introduced and its future in the healthcare environment discussed.

Correspondence: Nadine van Dongen
16 Grove Mansions, Clapham Common,
Northside, SW4 9SL, London, UK
Tel +44 77 923 74 077
Email nadine.vandongen@vandresearch.com

© 2009 van Dongen, publisher and licensee Dove Medical Press Ltd. This is an Open Access article which permits unrestricted noncommercial use, provided the original work is properly cited.

Quality standards

There is general agreement that widely accepted quality standards for medical care are lacking.[5] Guidelines and levels of compliance can be used to gauge quality standards in healthcare.

Guidelines

Whereas many specialty societies have guidelines, there are often substantial differences in the way various medical entities are managed; this is largely dependent upon standards of care within a given community. There is the belief that quality standards in healthcare ought to be almost universal because human beings are in essence similar. Especially in this era of evidence-based medicine, it is possible to gauge much more precisely which therapies offer benefits and those that do not. Evidence-based guidelines is the practice of evidence-based medicine at the organizational or institutional level. This includes the production of guidelines, policy, and regulations. This approach has also been called evidence-based healthcare.[6]

Widely published healthcare quality standards are, for example, those from the National Committee for Quality Assurance (NCQA), in the USA, and the National Institute for Health and Clinical Excellence (NICE), in the UK. These standards incorporate a high level of Evidence-Based Medicine but fail to go to the next important level, namely, the value aspect. The value aspect can be incorporated only by the actual users of healthcare therapies: the patients.

Compliance

Quality of healthcare can also be gauged through measuring the level of 'compliance' with a specific therapy. This shows whether a drug or therapy was given to the right person with the right explanation and the right information. Adherence to therapies is a primary determinant of treatment success.[7] Poor adherence attenuates optimum clinical benefits and therefore reduces the overall effectiveness of health systems. Non-compliance (non-adherence) to medication instructions, which is defined as the failure to take drugs as prescribed or failure to take them on time in the dosages prescribed, is dangerous and costly. Studies have shown that non-compliance may even cause more deaths annually than the major diseases. A rough estimate suggests that as much as 50% of drug prescriptions are not taken correctly.[7]

Why do people not adhere to therapy? There are several reasons, but some of the most important are:

- Forgetting to take the drug
- Not understanding or misinterpreting the instructions
- Experiencing side effects (the treatment may be perceived as being worse than the disorder)
- Denying the disorder (repressing the diagnosis or its significance)
- Not believing that the drug can help
- Mistakenly believing that the disorder has been sufficiently treated (for example, thinking an infection is over just because the fever disappears)
- Fearing adverse consequences from medication or dependence on the drug
- Worrying about the expense
- Not caring (being apathetic) about getting better
- Encountering obstacles (for example, having difficulty swallowing tablets/capsules, having problems opening bottles, considering treatment inconvenient, and being unable to obtain the drug).

Furthermore, non-compliance also adversely affects pharmaceutical companies. Although no precise estimates have yet been made, it is suggested that 15% to 25% of drugs prescribed are not even bought by the patient. This constitutes a huge loss to the pharmaceutical market. Moreover, this figure does not include the loss of market due to the disenchantment of the patients with therapy (ie, when therapy is not found to be beneficial, patients tend to suffer in silence rather than approach health practitioners). All these reasons for non-compliance have a common denominator: communication with the healthcare provider. When compliance is low, communication quality has to increase in order to improve general healthcare quality. Communication quality can improve only when one knows what is expected or demanded in terms of level of communication and manner of communication information. An aspect critical to any business is knowing what the customer wants by seeking their feedback.[8]

Therefore, the quality standards, guidelines and compliance currently used in the healthcare environment lack one essential component: the patients' experience and value.

The patients' voice

In order to help us to understand patients better and add the missing component in the healthcare environment, we should aim at retrieving their opinions and beliefs. Before exploring the impact and possibilities of the patients' voice, one should first acknowledge that patients are the core focus in healthcare. However, it seems there is not an automatic communication flow between all stakeholders. A strategic flow of communication with the right patients to the right stakeholders appears necessary to improve quality of care.

Areas where patient feedback comes into discussion can be categorized into three areas. The first area in which we should use patient feedback is *accuracy of information*, which is designed for and distributed to patients. The second area is *validating common beliefs and assumptions* of daily life experiences when having a disease or taking certain drugs. The final area, in which the patients' voice should be heard, is the *participation in decision-making* related to disease management.

Accuracy of information

Accuracy of information in itself is a quality assessment aspect. To connect this to patient feedback, it is suggested that organizations in the healthcare environment should involve patient feedback in order to check whether their information is accurate and relevant for the end-user of this information.

Education materials are often printed patient leaflets, websites, and articles in newspapers or magazines. These materials are used to enhance healthcare professionals' spoken information to patients. For example, asthma is one of the commonest chronic diseases managed in general practice, and many leaflets have been produced on its diagnosis, prognosis, management, and treatment, but these have been subjected to little critical review. A study on readability and accuracy of patient leaflets in the asthma indication showed that 20% of the leaflets contained inaccurate or misleading statements about areas outside the society guidelines. Six inaccurate leaflets were produced by charity organizations, the other five by drug companies.[9]

Testing with patients should be a routine procedure when creating such patient information, as it will reveal weaknesses and relevance levels of the information before bringing it to the broader public. When accuracy of information improves, trust and compliance increases and thus quality of healthcare will improve.

Validating common beliefs and assumptions

This area of patient feedback is an obvious one because validation of assumptions is vital in order to create a successful campaign for each organization. One of the most common mistakes in marketing is making decisions based on assumptions rather than facts. This should be avoided, especially in the healthcare environment that deals with diseases and health situations of people.

For example, a strategy on the awareness of diabetes in the United Kingdom based on measuring waist size would seem to be very understandable for everybody. But perhaps not everyone owns a measuring tape with which to check their waist measurement. Instead of spending millions on campaigning, some money should be spent on validating the assumption that 'measuring the waistline' appeals to people, and that the awareness and diagnoses of diabetes patients in any given country will dramatically improve, and thus effectiveness in healthcare too.

Participation in decision-making

The University of Pittsburgh Medical Center South Side has been seeking patient feedback to improve service, satisfaction, and patient safety. One initial finding is that patients demand good communication, including participation in the decision-making process, and timely response to concerns.[10]

Although this is a sensitive area for which patients to have a voice, it cannot be forgotten. The patient plays an increasingly influential role in the process of prescribing drugs. The internet has played a major role in shifting the balance of power in the doctor–patient relationship. The doctor is no longer the oracle. People are becoming more interested in lifestyle and drugs, and they know where to access the information. There is an increasing consumer awareness of drugs, which will eventually lead to a shift towards lifestyle products that patients will pay for themselves. The organizations in the healthcare environment need to understand the emotional side of their drugs or the 1 they are working with. While pharmaceutical research has traditionally been clinically focused, a shift towards research traditionally conducted in 'fast moving consumer goods' may be beneficial.[11] When patients are participating in healthcare decision-making, the boundaries should be stated clearly. A logical boundary can be the involvement in quality of life issues in the disease management concerning the patients' disease or ailment. By asking the patients how they believe their quality of life can be improved through medication or healthcare services, EQ5D scores can be improved dramatically.[11] Due to the fact that this subject is rather sensitive, it is recommended that boundaries be set after thorough discussions and research in the future.

The three areas in which it is possible to allow the patients' voice to be heard in order to improve efficacy in healthcare can be covered through qualitative or quantitative research. The aim of quantitative research is to classify features and construct statistical models in an attempt to explain what is observed. The aim of quantitative research is to validate the outcome through statistical significance. By carrying out

research in order to help integrate the missing component of the patients' experience and value into quality standards in the healthcare environment, one can increase efficacy in healthcare. Both quantitative and qualitative research can be used in this research. Every organization working the healthcare arena should consider whether they are compliant with involving the patient's voice in their strategy. In other words, these organizations should ask themselves the following question: 'are we patient-intelligent?'

Patient intelligence

Patient intelligence (PI) refers to the skills, technologies, applications, and practices used to help an organization acquire a better understanding of its position in the healthcare context. PI may also refer to the information collected by patients. PI applications provide historical, current, and predictive views of any given present situation on behavior and intentions of persons suffering from a disorder, disease. or complaint. Common functions of PI applications are reporting, analytics, health economic models, business performance management, benchmarks, patient brochure validation, and predictive analytics.

PI is often aimed at the support of better decision-making in the healthcare environment. Thus, a PI system can be called a decision support system.

The definition of PI is the ways in which we collect and use patient information. It encompasses the technologies, applications, and means for collecting, integrating, analyzing, and presenting patient data about beliefs and understanding of health status. The research outcomes can be used to report past patient information as well as predict future patient information, including trends, threats, opportunities, and patterns. Companies often need to outsource PI research, as legal aspects do not allow them to contact patients directly. Moreover, designing proper quantitative and/or qualitative research projects and implementing them can be quite complex.

It is important that healthcare organizations begin to lay the foundations on which to build PI so that through their chosen strategies they are able to reach the next level of sophistication. With an integrated understanding of the players and the dynamics of regional health economies, they will be better positioned for promotional innovation and managing long-term stakeholder relationships.[12]

PI can be used to ensure accuracy of information. For example, patients can be asked whether they understand a certain leaflet aimed at diabetes patients, or they can indicate what they miss in their disease management program. Also, common beliefs about how a patient reacts on drugs and/or how the disease is affecting his or her daily life can be validated or dismissed. For example, by asking 500 depressed patients how the side-effects of their antidepressants are affecting their daily life and that of their partner, the patient organization can decide to create a website specifically designed for partners of depressed patients. For participation in the decision-making of disease management, quantitative research can guide feedback in a structured way. Online fieldwork helps to cover certain disease dilemmas, especially the ailments that are considered as 'taboo' or include specific 'taboo' subjects that need to be discussed. One can think of questions on what patients endure with the management of erectile dysfunction or incontinence, or even how to cope with side effects of drugs, like sexual dysfunction when taking selective serotonin reuptake inhibitors.

PI applications can be used to improve compliance by working on the three areas described above. Furthermore, after this quality improvement, PI applications can even contribute to the acceptance of guidelines beyond regional acceptance. Healthcare providers might more readily accept guidelines, when they know they came about as a result of involving the patients' voices/views – in a methodical way – in their creation.

Future implications of patient intelligence

Because patients will continue to develop and become more knowledgable, they will become powerful stakeholders in healthcare, and PI will become more important in the foreseeable future. Healthcare organizations will be challenged by all stakeholders to develop structured pathways with which to integrate the patients' viewpoints into every process. In order to create a platform for patients and to ensure quantitative research is feasible, a specific 'patient intelligence panel' (PIP) is created in which patients can register to participate in patient intelligence research. This PIP can be utilized by all stakeholders in the healthcare environment. As a consequence, patients will not only make a difference, but any factors established that provide incentives for completing an online survey will be donated to patient organizations concerned with their disease or ailment.

Conclusion

Yes, 'let the patients talk' so that healthcare decisions become more effective! By using the patient's voice in research for numerous issues, healthcare organizations will be able to validate common beliefs about diseases. Additionally, they

can provide accurate information, which the patients can use to be more compliant and/or improve quality of life. When worked out in a structured way, the patient can be involved in the decision-making process related to their own disease management (within boundaries). These aspects will improve quality in healthcare through improving quality standards. This process of giving patients a voice can be described as patient intelligence.

Quantitative and qualitative research can be a platform from which to guide the patients' voice in a structured manner from within this new approach in healthcare. A special PIP can be used to operate quantitative research.

Disclosure

The author declares no conflicts of interest.

References

1. Clearly PD. The increasing importance of patient surveys. Now that sound methods exist, patient surveys can facilitate improvement. *Br Med J*. 1999;319:720–721.
2. Tasa K, Baker T, Murray M. Using patient feedback for quality improvement. *Qual Manag Health Care*. 1996;4:55–67.
3. Vingerhoets E, Wensing M, Grol R. Educational feedback on patient's evaluations of care: a randomised trial. *Qual Health Care*. 2001;10:224–228.
4. Wensing M, Vingerhoets E, Grol R. Feedback based on patient evaluations: a tool for quality improvement? *Patient Education and Counselling*. 2003;51:149–153.
5. Brown GC, Brown MM, Sharma S. Doctors must define quality in care. *Ophthalmology Times*. 1999;1;17–19.
6. https://exchange.utmem.edu/exchweb/bin/redir.asp?URL=http://www.amazo.com/EvidenceBasedHealthcare-J-Muir-Gray/dp/0443057214
7. Pateriya LP, Jha A, Munjal S. Application of information technology to overcome non-compliance of drugs URL: https://www.indianjournals.com/glogift2k6–1/theme_1article%201.htm. Accessed April 20, 2009.
8. Aaker DA. *Strategic Market Management*. New York: John Wiley & Sons; 1995.
9. Smith H, Gooding S, Brown R, Frew A. Evaluation of readability and accuracy of information leaflets in general practice for patients with asthma. *Br Med J*. 1998;317:264–265.
10. Fahy J. Health centres increasingly seek patient feedback to improve care. URL: http://www.post-gazette.com/pg/07143/788091-114.stm. Accessed April 21, 2009. pharmalivesearch.com.
11. www.vandresearch.com. Accessed August 23, 2009.
12. EuroQoL Group 1990. URL: http://www.euroqol.org.

Patient Intelligence

Publish your work in this journal

Dovepress

Patient Intelligence is an international, peer-reviewed, open access journal that characterizes and measures the central role of patient behavior and intention in optimizing healthcare management in all areas of disease and complaint types. An improved understanding of patient intelligence coupled with predictive analysis helps an organization contribute more effectively to achieving better outcomes.

The journal is characterized by the rapid reporting of reviews, original research, methodologies, analytics, modeling, clinical studies and patient surveys across all disease areas. The manuscript management system is completely online and includes a very quick and fair peer-review system. Visit http://www.dovepress.com/testimonials.php to read real quotes from published authors.

Submit your manuscript here: http://www.dovepress.com/patient-intelligence-journal