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Cover Page Footnote

The first author is also the patient referred to in this article. The open and transparent conversations with the dermatologist at the local hospital, and the care teams of the university hospital were highly appreciated and contributed to a smooth treatment process, resulting in a high level of patient satisfaction. This article is associated with the Quality & Clinical Excellence lens of The Beryl Institute Experience Framework (<https://www.theberylinstitute.org/ExperienceFramework>). You can access other resources related to this lens including additional PXJ articles here: http://bit.ly/PX_QualityClinExc

A patient perspective on information provision during the care path of Lentigo Maligna

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Abstract

Patients sometimes experience complex diagnostic and treatment procedures. During these processes, they need to rely on the information provided by the care providers. In particular, if they would like to play an active role in the shared decision-making process, it is important that this information is accessible, complete and understandable. A patient with Lentigo Maligna on the nose has been followed during the process of diagnosis, shared decision-making and treatment. Using the autoethnographical methodology, it was evaluated which sources of information available to the patient contributed to a better understanding, a more active role in the treatment process and a positive experience. Possible improvements are suggested.

Keywords

Lentigo Maligna, patient experience, patient portal, PHR, EMR, shared decision making, Breuninger, flap reconstruction

Introduction: The Information Provision for Patients

Patients usually receive their medical information from the care provider in the following four ways: 1) verbal communications with the caregivers about test results, treatment options and progress; 2) telephone conversations with hospital employees, usually to report results or outcomes and to report on updates or incidents; 3) letters and notes about decisions and treatment plans, or to confirm appointments; 4) the patient portal of the electronic medical record.

Patient portals are relatively new applications and are developed as an extension of the Electronic Medical Record (EMR) of the care providers^{1,2} In most cases, the patient portal (PP) is only a subset of the complete EMR, as many care providers are reluctant to give access to the full medical record for various reasons³ Access to the full medical record, either in print or in electronic form, has been regulated in most countries to the extent that the complete records can only be obtained through (written) request. Health care institutions that offer their patients access to all medical information, including the physicians' notes, report a reduced number of malpractice cases,^{4,5} while their patients report higher engagement and satisfaction rates.⁶ Whether patients have access to the full medical record or only to selected information through the patient portal, the purpose is to improve the medical information flow so patients can play a more active role in

their treatment process and feel more actively engaged in their own care.⁷

It is not unusual for patients to have different care providers based in different health care settings, and access to many different EMRs or PPs. Lack of uniformity and standardization of systems, lack of interoperability between systems, and differences in reporting by care providers, make it difficult for patients to obtain and maintain a complete overview of their medical information. This becomes even more important with age as the amount of data generally increases due to comorbidity. To overcome this problem and to be able to collect all relevant medical information from various health care institutions and/or departments, patients can collect the available data in a personal health record (PHR). Ideally, a holistic PHR not only contains all relevant medical information as collected by the patient over all disciplines and health organizations, but also allows the patient to add personal information or comments. This will lead to patients who are more engaged in their own care, which will lead to better clinical outcomes and increased patient safety.^{7,8}

Additionally, patients can enrich their data set by consulting the internet and search for more information on their specific diagnosis and treatment options. Interpretation of information available on professional websites can be challenging for people who lack medical education and are unfamiliar with medical jargon.

Understanding of medical information by patients is strongly related to their literacy or that of their family members.⁷ Finally, information provided through patient expert groups could also contribute to acquiring a more complete overview.^{10,11}

The objective of this article was analogous to the method of autoethnography, to use the patient experience to describe and interpret the way in which medical information was provided during the diagnosis and treatment path, and how this contributed to reach a level of understanding through which he was able to participate in his own care. Autoethnography¹² is a qualitative research method that uses personal experience (“auto”) to describe and interpret (“graphy”) cultural texts, experiences, beliefs, and practices (“ethno”). Although this methodology has not yet been used frequently to describe and interpret medical or health care related practices, we agree with Miranda that it is a useful way to learn from the patient experience and improve interactions between patients and the medical team, leading to more engaged patients, better clinical outcomes and improved patient safety and satisfaction.¹³

Definitions

An Electronic Medical Record (EMR) is set up to contain the full set of test results, reports on consultation, scans and photographs and the conclusion of the treating care provider as well as personal health related data.¹³ A patient portal (PP) is a tool for patients to access (parts of) their EMR and is generally made available by the health care organization. The portal may also be used as a service point for the patient to keep track of appointment scheduling and questions for care providers.

The personal health record (PHR) is an electronic or paper collection of data directly related to the health and disease process of a patient, such that it may assist the individual concerned in taking informed decisions about health and treatment. The patient owns and manages the PHR and determines the rights of access either in print or in a secure environment. Ideally, the PHR is a complete set of data and contains all information gathered by the patient from all sources available as well as personal health information, the patient story and relevant information related to the disease and care process.

Lentigo Maligna (LM) is an in situ type of melanoma which occurs in sun-damaged skin, frequently on the face or neck.¹⁵ LM evolves slowly over the years and progresses into an invasive malignant melanoma (LMM) in 2.5-5% of the cases. It usually occurs in older individuals with a peak incidence between 65 and 80 years; however, significant increase is being reported among people aged 45 to 64 years. US data show that the incidence of LM has increased from 2.2 per 100,000 per year in the period

1970-1989 to 13.7 per 100,000 per year over the period 2004–2007.⁸

LM presents itself normally as an a-typical, pigmented, macular lesion¹⁶ on sun- damaged skin. Surgical excision with sufficient margins is considered treatment of choice. However, when LM manifests itself on certain body parts such as the nose or eye lids, where there is little room for surgical excision with the required margins, it becomes a more complicated procedure due to the need of plastic reconstructive surgery to repair the excision zone. For patients who are unable to undergo surgical excision, alternative treatment options include radiotherapy, topical imiquimod, cryosurgery and laser therapy or a combination of topical imiquimod and excision. Surgical excision has the lowest five-year recurrence of 6.8% compared to 31% for radiotherapy.¹⁷

The Medical Journey

At the time of diagnosis, the patient was 67 years old. He owned a university degree in biochemistry and after retiring had started to participate in a PhD program investigating the effect of information provision on the interaction between patients and their caregivers. After confirmation of his diagnosis of LM, he was determined to engage as much as possible in his own care and to actively participate in the shared decision-making process, as he knew from the literature that this would improve clinical outcomes and patient safety.⁵

The first biopsy of the pigmented spot was carried out at a local hospital in 2009 and reported as Lentigo Benigna (LB). During subsequent years, biopsies were taken every three years to track progress. The affected area slowly increased in size over the years and in 2019 had grown to the extent that the patient decided he wanted it removed for cosmetic reasons (Figure 1).

Before doing so, another biopsy was taken and the lesion was identified as LM. After consultation at the local hospital, the patient was referred to a Multidisciplinary Oncological Team (MOT) at a university medical center for further diagnosis and treatment. The team consisted of

Figure 1. Lentigo Maligna on the nose



2 dermatologists, an oncologist, a radiotherapist and a plastic surgeon, while a number of interns attended as well.

There are number of important information steps in the process.

- Biopsy was taken by the dermatologist of the local hospital and sent to the pathology department of the same hospital.
- Pathology results were communicated to the dermatologist of the local hospital. These were subsequently communicated verbally with the patient and electronically through the portal and with the MOT.
- The consultation of the MOT resulted in a new biopsy, as they communicated that the macroscopic aspect of the lesion appeared as Lentigo Benigna (LB) instead of LM. In addition, they requested the pathology department of the local hospital to send them the materials from previous years so diagnosis could be (re)confirmed. The conclusion was that LM was present in all biopsies, also those from previous years. This was communicated verbally to the patient. The patient portal of the local hospital mentioned LB until 2019. To the patient, it was quite shocking and emotional learning the spot had been LM for over ten years. Should the diagnosis have been correct 10 years earlier, the spot could have been removed much easier due to its smaller size and with significantly less medical, physical and emotional impact.
- Treatment options were communicated verbally with the patient: radiotherapy, topical imiquimod application and surgical excision followed by plastic reconstructive surgery. The medical team recommended the latter option because of the high probability of success.
- In order to be better prepared for active participation in the decision-making process, the patient consulted UpToDate.¹⁸ According to UpToDate, surgical excision and subsequent plastic surgical reconstruction is considered first choice treatment. Success rates are 98 to 100% after 38 months. Topical imiquimod therapy or radiotherapy excision are second choice options for those patients who are unable to undergo surgery. Although laser therapy and cryosurgery were mentioned as options, no scientific studies were reported.
- After consulting UpToDate and subsequent discussions with the team, the decision was reached to opt for excision.
- The surgical technique proposed was the Mohs/Breuninger methodology. Using this methodology, excision of the lesion is performed starting with small margins after which pathology results of the tissue lead to either repeat excisions with larger margins until all malignant tissue is removed or subsequent plastic reconstructive surgery using the flap

technique. According to Schnabl et al, patient overall satisfaction levels for this procedures are good to very good for 86% of the older population, age over 60 years and reconstruction with a forehead flap.¹⁹

- The processes carried out by the dermatologist and the plastic surgeon required joint planning and interactive communication from the beginning and through the entire process. This caused some concern with the patient, as it meant that he would be walking around with a fairly large defect on the nose for several weeks, i.e., the weeks during which the Breuninger excision treatment was taking place at the dermatology department, with pathology result of the tissue leading to either additional excision or scheduling the appointment with the plastic surgeon. Knowing about the various waiting lists, the patient was worried that he might have to suffer pain for many weeks due to a large open wound on the nose (Figure 2). In the end, it all worked out well, and there was fairly little waiting time between the last pathology results and the plastic surgical intervention, which was a relief for the patient.
- The total process was estimated to take 3 months but took 4 months from diagnosis to removal of the last stitches after flap reconstruction.
- Checkup appointments 3 months after the surgery by the plastic surgeon were carried out.
- A final scar correction, although planned after 6 months, was delayed due to Covid-19 and finally took place one year later.
- Annual skin checks in relation to potential other LM spots were scheduled with the local dermatologist.
- Total recovery time was estimated to take over a full year after diagnosis.

Information Collection: The Portal versus other Sources

After receiving the diagnosis of LM, the patient started to look for opportunities to adequately inform himself about the treatment options available. The patient portal of the local hospital only showed short comments on the

Figure 2. Skin defect on the nose after Breuninger excision treatment and before plastic surgery



consultations and did not present suggestions for further background reading. The university hospital portal had more functionalities and included scheduling of appointments. It also included a question-and-answer module, but this was not embedded in the physician's working process. So questions raised in the portal were not answered. Most terms used in the reporting were high-level medical terminology. As data from the portal is taken from the EMR, it reflects the physician's purposes and ignores patient needs and participation.

The patient, therefore, started to consult the internet using Google scholar. One of the sources mentioned was UpToDate. UpToDate is available in a patient and a physician version. Only limited text is available for free, and access to both versions can be obtained through a subscription, the physician version being more extensive and expensive. In this case, the physician's version was used. Other suggested references were checked and, when considered relevant, the scientific articles were consulted using the university library. In particular, the full text of the articles were checked for success rates, side effects and clinical effectivity. For the (plastic) surgery process, articles

were consulted for treatment and patient satisfaction rates.¹⁹ In addition, information regarding the publication activity of the surgeons and dermatologists involved was collected to obtain insight in their experience and knowledge levels with the methodology suggested. All data was added to the patient's own created PHR in electronic as well as paper format.

During the treatment process, regular consultations with the treating physicians were held, which either were reported in the EMR and sometimes as an abstract in the patient portal. Notes were taken by the patient. After finalizing each major step in the procedure of the treatment pathway, a copy of the hospital EMR was requested to check for completeness; this also included photographs taken during the Mohs/Breuninger surgery. At regular intervals, the patient himself took photographs of the wounds to monitor progress of the healing process. After adding all the information to the PHR, a comparison was made between the various information sources available (Table 1).

Table 1. Comparison Between Information Sources

Source	Available Information	Preferred but Missing Information
Local hospital portal	Short reports by the physician (summary of the consultations with the patient, physician's remarks, mostly short sentences)	Results of diagnostic tests Appointment scheduling Medical conclusions and suggested treatment plan Older data unavailable
Local hospital EMR (obtained through physician)	Physician reports Results of diagnostic tests Treatment plan	Data from the paper archive
University hospital portal	Physician Reports Q&A section Appointments Some lab results	Microbiology and pathology results as well as medication list Photos
University EMR (obtained partly in paper format, partly on CD)	Clinician's Reports Medication list Photos All lab results	With regard to the plastic surgery, no report is given about the intervention other than "surgery went well"
Medical team	University hospital website mentioned skills of the medical team with sometimes a summary of scientific career	Linkedin and Google scholar searches were needed to find out more about the team with regard to publication activity
Scientific articles	UpToDate and other articles	Open access is accessible and paid access through university library
PHR	Complete information Paper file with electronic backup (scans)	Interoperability difficult in digital format

Discussion and Conclusions

Involving patients in their care is an important factor to improve health care outcomes, reduce disease related stress and enhance patient satisfaction. Patient engagement means encouraging patients to actively participate in shared decision-making interventions, providing care management support and training for family caregivers, as well as tailoring patient information and education to accommodate patients' health literacy levels.⁵ Providing patients with timely, accurate and relevant medical information and access to their records is an essential factor in the engagement process. The information provided needs to be complete, clear and understandable and ideally includes the physicians' notes.²⁰ However, care providers tend to write only short sentences, mainly summaries of their interaction with the patient, and their interpretation of results. This information is usually visible to the patient through the patient portal, which is often used as the main sources of information for the patient and seen as a documented version of the verbal consultations. By offering access to the full EMR, the patient would obtain more complete insight in the disease process, treatment options and considerations of the care provider. Patient involvement will be increased when care providers are actively encouraging patients to consult the information provided and explain that their involvement will help in producing the desired effects.²¹ The patient was determined to be actively involved in his own care and the medical team certainly had the intention to practice shared decision making and explain the various treatment options and consequences. However, based on the data provided by verbal consultations, the PP and EMR, either at the local or university hospital, the patient felt he had insufficient information to be able to fully participate in the shared decision-making process in an informed way. The UpToDate information obtained by the patient proved to be a useful additional source for him, as it was complete, digestible and offered a wide range of references for patients to consult. This additional scientific information contributed significantly to becoming aware of treatment options and implications and helped in reaching a balanced decision. Even though this type of additional scientific and professional information is generally only available through a library, unless articles are open-access, the patient was able to access the information as he was working as a PhD researcher at a university hospital.

Going into the surgical process, both by the dermatologist and the plastic surgeon, the patient felt he was well prepared thanks to the multiple conversations with the medical teams and the extensive literature search he had done himself. However, after the plastic surgical reconstruction, he realized that he had not been well-prepared for the postoperative situation. For example, he did not know that with this method it is of utmost

Figure 3. Forehead flap reconstruction “bridge”



importance that blood vessels of the flap or “bridge” not all be coagulated during surgery, as an adequate blood supply from the forehead to the skin graft on the nose is essential for recovery. This meant living with a large wound that was constantly leaking blood for about a week, causing stress and sleepless nights (Figure 3).

He was also unprepared for the fact that, because of the bridge, he would not be able to wear his glasses, which caused him discomfort in normal life. In addition, the cosmetic aspect of the face during the time the bridge existed was such that many people could not look at him without being uncomfortable, which had a significant social impact. Should he have had the opportunity to, for example, connect with patient expert groups prior to the surgery, he would have been better prepared for these temporary inconveniences leading to a better overall acceptance and enhanced experience of the procedure. The final result is shown in Figure 4.

Figure 4. End result 22 months after diagnosis



As the medical information sought was scattered over different PP's and EMR's, as well as the internet, the patient collected all information about the disease in a self-built electronic and paper personal health record (PHR) to create a complete overview of the disease process and treatment. As no example of a PHR was available, the version was created partially based on the design of the Batz Foundation guide.²² Recently, certain patient interest groups, for instance diabetes and bowel disease, have taken steps to create specific apps to assist patients in creating an electronic PHR. Unfortunately, these PHR's focus on specific diseases only and will be more difficult to use with age and enhanced comorbidity. An ideal and complete PHR should contain all the hospital data of the portal, regular updates from the full EMR, relevant internet resources, personal meeting notes, photographs and audio information. The PHR may also contain other data such as information about the medical team, scientific articles, flowcharts, financial and insurance documentation relevant to the disease process. In the future, highly interactive electronic PHR may also provide for options to add data on mood, pain, stress and data from wearables to complete the picture.⁸ Eventually, full electronic and interoperable PHR's might become available for patients and their family members to use during their disease and aging process.

It was concluded that the patient portal, a tool that is generally offered by health care institutions to patients as the suggested way to access their medical data, contained insufficient information to adequately inform the patient about his disease and treatment options. He felt he needed to collect additional information to be able to fully engage in the shared decision-making process with the treating physicians.

It is suggested that the patient portal could be extended to contain more information, including physicians' notes and used in a more interactive manner, offering links to relevant and easily accessible additional medical and scientific information. This could provide for a more efficient and interactive process between patient and care givers, resulting in a better patient experience and increased patient satisfaction. In addition, and especially for those patients who have several caregivers in different hospitals, it would be helpful to offer models of personal health records to collect all the data and create an overview that will help in the understanding and the shared decision-making process.

Although there is some debate if a single patient experience can be translated to the broader patient group, this article builds on the scientific results of the patient as an investigator at Erasmus University and also aims to contribute to a solid knowledge base for patients with Lentigo Maligna. It may, therefore, not only serve as an information source for patients and relevant patient expert

groups, but also provide them with inside in the importance of information exchange and the active role they can play in becoming well-informed and actively engaged in their own care. Additionally, it provides patients with suggestions for dealing with practical issues and information usage in general when dealing with digital health care information systems.

Recommendations

The general lack of validated (scientific) information in the hospital patient portal needs further research, in particular the question how upgrading this information would contribute to patient engagement, satisfaction and efficacy of treatment. A suggestion might be to provide a direct link to relevant UpToDate sections as standard option in the patient portal or specific information as provided by the care provider. Alternatively, more patient friendly options, such as graphs and instructions for treatment, might be useful and could include measuring the impact on patient behavior, level of shared decision-making and adherence to treatment.

Although some efforts are being carried out to design PHR's, more thorough design research is needed to create suitable ones. The PHR's, generally created per incident, disease or organization, need to be constructed from a holistic point of view and based on a range of standard building blocks so the PHR can be used and developed in real time during one's life span. A design study is recommended.

The European Cancer Patient Advocacy Network is actively promoting the contributions of patients to the scientific literature.²³ Also, the British Medical Journal is encouraging patients to contribute to the scientific literature under the initiative "What are patients thinking?"²⁴ It is suggested to support more patient reported outcomes in science such as the BMJ initiative. The use of an adapted form of the Autoethnography methodology, to describe and interpret medical or health related practices, should be investigated.

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The open and transparent conversations with the dermatologist at the local hospital, and the care teams of the university hospital were highly appreciated and contributed to a smooth treatment process, resulting in a high level of patient satisfaction.

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