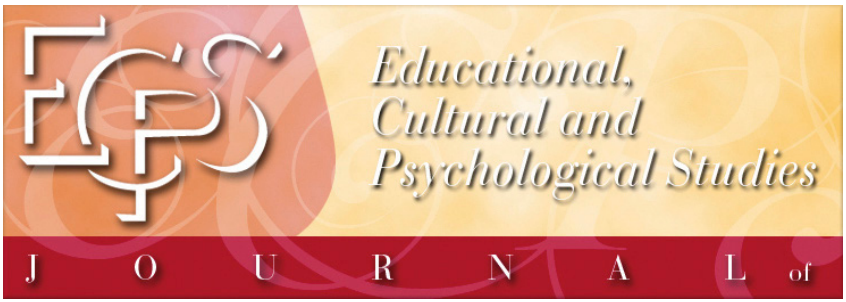

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Note di Ricerca
Research Notes

Commenti, Riflessioni, Presentazioni, Resoconti, Dibattiti, Interviste
Comments, Reflections, Presentations, Reports, Debates, Interviews

Adult Patient Education: A Readability Analysis of Hospital University Campus Bio-Medico's Patients Information Materials (PIMs)

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EDUCAZIONE DEL PAZIENTE ADULTO: ANALISI DI LEGGIBILITÀ DEL MATERIALE INFORMATIVO DELLA FONDAZIONE POLICLINICO UNIVERSITARIO CAMPUS BIO-MEDICO

Abstract

The UCBM's nurses and doctors have produced patients information material under the form of brochures that we delivered to patients in order to help them better understand their pathology, therapeutic path and procedure to which they will have to undergo. With the Covid-19, doctors necessarily spend less time with patients. This means that patients tend to (mis)inform themselves on internet. We analyzed the PIM's text readability with the Gulpease index. We submitted a qualitative questionnaire to 100 patients to evaluate the clarity of presentation and the communicative effectiveness and how much these allowed or not them to face their procedure with greater clarity and serenity. Brochures aroused interest in 77% of patients, where 87% declared that «The concepts are clear and I could understand them», 55% indicated that «The information is useful for

understanding my condition». None of the them reach 40 pt. of the Gulpease index. Furthermore, the institutional font size was too small. Education of adult patient is a transversal area of pedagogy, medical clinic and communication. Experts from various fields (including patient associations) should collaborate to create informative materials that are useful for both patients and doctors/nurses.

Keywords: Comprehension; Covid-19; Health education; Patient education; Patient information materials.

1. Introduction

The time available to health professionals (doctors and nurses) dedicated to patient education has gradually decreased until 2020.

Since 2020 with the Covid-19 pandemic, operators have begun to spend even less time in contact with patients.

This means that patients tend to (mis)inform themselves using the ever available world wide web search engines (Google, Yahoo, Bing, etc.) through an array of electronic gadgets.

So, doctors need to engage trust with their patients which is crucial to the success of any personal or professional relationship (Hogikyana, 2021).

In healthcare, trust is associated with patient provider communication, seeking and submitting to care, increased adherence to treatment recommendations, and/or remaining with and recommending a physician (Trachtenberg, 2005).

The Hospital University Campus Bio-Medico (UCBM) produced information brochures (according to the Joint Commission International Standard's PCC.5: «The hospital provides an education program that is based on its mission, services provided and patient population, and health care practitioners collaborate to provide education») that were delivered to patients to help them better understand their pathology, the therapeutic path and the procedure to which they will have to undergo.

Research was conducted, as approved by the Ethics Committee, to study the patient's perception of the information material.

We decided to study how patients understand (or not) our PIMs.

We started from the JCI's Standard PCC.1.1: «The hospital seeks to reduce physical, language, cultural, and other barriers to access and delivery of services and provides information and education to patients and families in a language and manner they can understand» and we wandered about how, our «information & education materials» were perceived.

We know well that admission as an inpatient to a hospital or registration as an outpatient (for example, in the emergency department or ambulatory clinic) can be frightening and confusing for patients. Patients may find it complicated and confusing when attempting to access care and understand their rights and responsibilities in the care process.

We wanted to implement a process to eliminate or to reduce barriers because, when written communication is not effective or appropriate, can lead to mistake or near miss.

So, we decided to analyze our PIMs as the Measurable Elements of PCC.1.1 states:

- «Information about aspects of the patient's medical care and treatment are provided in a manner and language the patient understands»;
- «Information about patient rights and responsibilities is provided to each patient in writing or other method, in a language the patient understands».

We used an analysis sheet for the readability of the text, evaluating for each brochure the quantity of images, type of images used, type of font used, font size, the background and text's colors, the use or not of references, etc. Subsequently, an analysis of the text of each individual brochure was also made with the Gulpease readability index.

We submitted a qualitative questionnaire to 100 patients, in order to evaluate the clarity of presentation and the effectiveness of communication and how much this assisted them to face their procedure with greater clarity and serenity.

The last part of the questionnaire was dedicated to collect any suggestions from patients in order to modify and improve the quality of information presented. We evaluated the effectiveness of 5 brochures that UCBM delivers to its patients (leaflet for patients undergoing: inguinal hernioplasty, eye surgery, bariatric surgery, prosthetic surgery of knee, chemotherapy patients). We also evaluated the perception that patients have of the graphic quality.

Williamsons (2010) suggests that PIMs remain the most frequently used sources of medical information (Meredith, 1995; Kenny, 1998).

How people respond to healthcare information crucially depends on how this information is designed (Fuchs, 2007; Pander, 2010).

They have multiple benefits to patients including helping them understand what is wrong, gaining a realistic idea of progress, to provide reassurance and to help them cope (Duman, 2003). They also assist in self-care by legitimizing help-seeking and concerns (Duman, 2003).

Patient education materials also positively influence knowledge and satisfaction (Gibbs, 1989) and can reinforce verbal communication between health care providers and patients (Clerehan, 2006; Hirsh, 2009).

The aim of patient education in general is more than knowledge transfer and disease control, it also enables the participants to: (1) understand the illness process, (2) acquire skills related to medical and disease management, (3) adjust treatment to their condition and (4) maintain quality of life (Lorig, 2003).

PIMs may contain complex medical terminology, which can be confusing to patients and not be fully understood (Paasche-Orlow, 2003).

The recommended level for provision of patient medical information is at US grade 6 (11-12 years), although the national reading age is US grade 8-9 (13-14 years) (Kirsch, 2002; Badarudeen, 2008; Wilson, 2009).

Most adults read at an eighth-grade level, but the American Medical Association (Weiss, 2007), the National Institutes of Health, and other health organizations recommend that patient education material should be written at less than a sixth-grade reading level.

Despite this recommendation, most (if not all) studies focusing on the readability of patient education materials have demonstrated that the readability of such resources is too low (Wallace, 2005; Badarudeen, 2008; Sabharwal, 2008; Bluman, 2009; Vives, 2009; Wang, 2009; Yi, 2013; Feghhi, 2014). Low health literacy has been associated with poor health outcomes, more frequent and longer hospitalizations, more complications, noncompliance and increased healthcare costs (Dewalt, 2004; Berkman, 2011; Serper, 2014).

Moreover, appropriate reading levels are a factor that can impact the effectiveness of patient education materials (Hirsh, 2009). We know that health literacy plays an important role in patient understanding and health outcomes. The majority of people in the general population e.g. Australia: 59% (Australian Bureau of Statistics, 2009); Europe: 47% (Sorensen, 2015); Canada: 60% (Rootman, 2008) have inadequate health literacy to access, comprehend and act on reliable health information and the proportions are even higher in older people (Chesser, 2016). This is associated with poor self-management, less access to the health system, increased chronic disease, reduced adherence to medication and increased medication related harm (Parekh, 2018). It is therefore important to specifically address the needs of patients with low health literacy (Berkman, 2011; Australian Bureau of Statistics, 2015).

Stenberg *et al.* (2018) reviewed relevant literature published between 2000 and 2016. They paid attention to variations in study, intervention, and patient characteristics. Of the 4693 titles identified, 56 articles met the inclusion criteria and were included in this scoping review. Of the studies reviewed, 46 concluded that patient education interventions were beneficial in terms of decreased hospitalization, visits to Emergency Departments

or General Practitioners, provide benefits in terms of quality-adjusted life years, and reduce loss of production. Eight studies found no health economic impact of the interventions. The results of this review strongly suggest that patient education interventions, regardless of study design and time horizon, are an effective tool to cut costs.

They found that 82.1% of the studies reported that patient education interventions resulted in impact or effects as measured by one or several health economic outcomes. Eight studies (14.3%) found no health economic impact of the interventions. In addition, one study (1.8%) showed only small improvements in QALY (Lambert, 2010) and one study (1.8%) found short term effects after 1 year, but no differences at the second and third year (Hagen, 2003). The results show that patient education interventions were beneficial in terms of decreased hospitalization, visits to Emergency departments or General Practitioners, increases in QALYs, or reduced loss of production.

Also business companies produce PIMs, Yi *et al.* (2017) reviewed a total of 581 orthopedic patient education materials from the 5 largest implant manufacturers. The mean overall Flesch-Kincaid readability test (FK) grade level was 10.9 (range, 3.8-16.1). Only 58 articles (10%) were written ≤ the eighth-grade level, and only 13 (2.2%) were ≤ the sixth-grade level. The mean FK grade level was significantly different among groups (Smith & Nephew = 12.0, Stryker = 11.6, Biomet = 11.3, DePuy = 10.6, Zimmer = 10.1; $p < .0001$). This means that most patient education materials from implant manufacturers are written at a level too high to be comprehended by the average patient.

Amini (2007) assessed the readability of the American Academy of Pediatric Dentistry's (AAPD) patient education brochures and compared their readability level with that recommended by health education experts. They studied the readability for the 25 AAPD brochures using the: (1) Flesch-Kincaid formula; (2) Gunning Fog formula; and (3) Flesch reading ease formula. They compared these results to the reading level recommended by the experts. They found that the mean readability for all 25 brochures was: (a) 9.1 (+/-1.8 SD) using the Flesch-Kincaid formula; (b) 9.2 (+/-1.5 SD) with the Gunning Fog formula; and (c) 53.0 (+/-12.2 SD) with the Flesch reading ease formula. Using the Flesch-Kincaid and Gunning Fog formulas, 88% and 92% of the AAPD patient education materials were written above the recommended sixth-grade reading level, respectively. Overall, American Academy of Pediatric Dentistry patient education materials were difficult to read and written above the recommended level for the general public using accepted measures.

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Italian laws (Article 32 of the Italian Constitution and Law of 22 December 2017, n. 219) establish that the consent to a procedure must be preceded by adequate information regarding the characteristics, risks and purposes of the procedure.

Informed consent is therefore an expression of conscious adherence to the health treatment proposed by the doctor; and being aware is a person's right.

Finally, it should also be emphasized that the Italian legal system with Law n. 145 of 28 March 2001, ratified the Oviedo Convention of 4 April 1997 on human rights and biomedicine. This dedicates Chapter II (Articles 5 to 9) to the definition of Informed Consent, in which it is established that: «An intervention in the field of health cannot be carried out until the patient has given free and informed consent. This person receives adequate information on the purpose and nature of the intervention and its consequences and risks» (Article 5).

Joint Commission International's PCC.4.3 standard established that patients and families must receive adequate information about the patient's condition, proposed treatment(s) or procedure(s), and health care practitioners so that they can grant consent and make care decisions (JCI, 2020).

When informed consent is required for the treatment(s) or procedure(s), the following elements are included in the informed consent process and explained to the patient prior to obtaining consent:

a. the patient's condition;
b. the proposed treatment(s) or procedure(s);
c. the name of the person providing the treatment;
d. potential benefits and drawbacks;
e. possible alternatives;
f. the likelihood of success;
g. possible problems related to recovery;
h. possible results of non-treatment.

This information must be clear and transmitted in a language that the patient can understand, as in most cases there are elderly patients, patients who have never had experience in the healthcare, or patients who are afraid and bewildered.

Very often patients do not understand what the doctor is saying to them or they have not had enough time to talk in depth about their symptoms (Ley, 1992); they quickly forget what the doctor told them and once they leave the room they realize that they have not understood the information correctly and therefore, from that moment on, their anxieties, fears and worries increase rather than decrease.

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This entails the fact that the patient is confused. He has not understood what he is feeling or what is happening to him, consequently he does not know how to proceed in order to heal himself. So, to be able to understand something about his pathology, Internet remains the only tool available to him, accessible to each person in a very simple and quick way also using personal mobile devices. It happens, however, that many web-sites are not suitable or the information they contain is not accurate; although there are several organizations that certify the health content of the sites (such as the HON code), but few patients notice those differences.

Patient education improves the patient's feeling of trust and control. It helps building a therapeutic alliance between the patient and the health-care staff, allowing patients to actively participate in their care.

Written materials have the following advantages: they allow patients to learn at their own pace, to process information according to the time it takes for each of them, and to share information with others. The use of written educational material is considered a cost-effective and time-efficient method of delivering health messages.

Information is an important tool to alleviate any patient's suffering, anxieties, fears and worries, which often accompany the patient and their family members who must deal with an illness. Informing patients should be considered a common activity inside the care process.

Therefore, for a clear health communication we must avoid medical terminology (Pfizer, 2004), we must focus on a few key information, we have to effectively involve patients in the discussion and have confirmation of their real understanding (repeat-back, summary-back).

When we provide information to patients and their families, we should consider all aspects that could reduce their ability to understand and integrate the information that is important to them. This is why some hospitals started collaboration with patient associations when revising the texts of their brochures.

2. Methods

With this study we aimed at evaluating the effectiveness of Hospital's PIMs in improving: communication and information in the doctor-patient relationship, the patient's perception of this educational tool and the graphic quality.

Like many health care providers, our hospital has a wide-range of PIMs for patient use. All of these booklets and leaflets have a similar layout, with the same font and style (Williamson, 2010).

For the analysis we used:
1. qualitative-quantitative questionnaire;
2. analysis sheet of the images and the contents of the brochures;
3. online calculation of the Gulpease index.

Target: 100 patients.

Divided into the following age groups (*Fig. 1*):

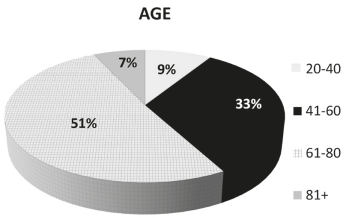

Figure 1. – Age gropus.

The hospital's website was used as a source of PIMs.

5 of 56 available booklets were downloaded. This information was mostly general about patient's conditions, procedures, treatments and background information about the hospital. Specific data about medications was not assessed. Microsoft Word (Word 2000, Microsoft Windows XP Home Edition) was used to provide the Gulpease's reading statistics – this automated software has been proven to be reliable and valid. The readability of each form in its entirety was assessed and the patient's statement section was assessed separately. In addition, we asked to patients to answer to a brief questionnaire about PIMs.

However, everything is designed with a practical functional implication: doctors and nurses will take the time of the visit or medication only to respond to any doubts and requests for clarification from patients «educated» by having read the brochure (and not to educate them during the visit).

Clinical Units PIMs: General Surgery (inguinal hernioplasty), Ophthalmology (eye surgery), Bariatric Surgery, Orthopedics (knee prosthesis), Oncology (patients being treated with chemotherapy).

2.1. *Qualitative-quantitative questionnaire*

We asked patients to evaluate: the clarity of presentation, the effectiveness of communication of the information materials and any help received to face the procedure with greater clarity and serenity.

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The questionnaire consisted of 14 questions (that we extracted from the Pfizer's *Principles for clear health communication*, 2004):
- n. 1 multiple choice;
- n. 5 questions with 5-position Likert scales;
- n. 3 dichotomous answer (yes/no);
- n. 3 10-position attitude scales;
- n. 2 open questions to collect opinions and suggestions for improvement.

2.2. *Sheet analysis*

We used an analysis sheet for the «readability» of the text analysis. We evaluated number and type of images used, the type of font, the size of the font, the text and background color's, the use or not of scientific references.

2.3. *Gulpease index*

We analyzed the text of each individual booklet. We used the Gulpease readability index that evaluates the readability of a text calibrated to the Italian language (Lucisano, 1988).

This index, compared to others, has the advantage of using the length of words in letters instead of syllables, simplifying the automatic calculation. It was defined in 1988 as part of the research of the GULP (University Linguistic Pedagogical Group) and considers two linguistic variables: the length of the word and the length of the sentence with respect to the number of letters.

The formula for its calculation is (*Fig. 2*):

$$89 + \frac{300 * (\text{number of sentences}) - 10 * (\text{number of letters})}{\text{Number of words}}$$

Figure 2. – Gulpease index.

The range is from 0 (*lowest readability*) to 100 (*highest readability*). Scores below 80 are difficult to read for people with a primary school certificate; below 60 are difficult to read for middle school graduates; below 40 are difficult to read for people with a higher degree.

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3. Results

The statistical survey showed that reading the brochure aroused «interest» in 77% of patients, «relief» in 24%, «curiosity» in 16%, only 3% of patients feel «no emotion» after reading the brochure, no one replied with the answer «negative feelings» and «worries». Finally, only 1% believe that reading the brochure has aroused «anxiety» (*Fig. 3*).

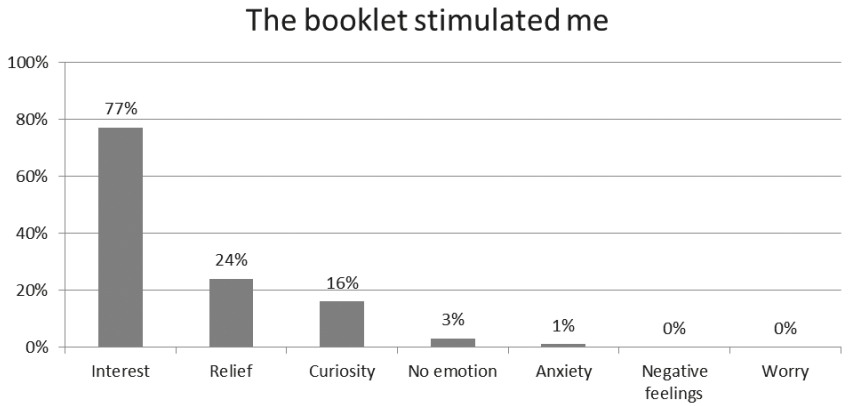

Figure 3. – Booklet stimulation.

We asked about the contents' expression: 87% of people declared that «The concepts are clear and I could understand them», 55% that «The information is useful for understanding my condition», 49% replied that «Information is useful to better deal with problematic situations», 48% stated that «The technical terms and abbreviations are explained and understandable», finally only 1% stated that «The information is not useful for dealing with problematic situations».

None has selected: «The concepts are difficult and hard to understand», «The technical terms and abbreviations are not explained or are not understandable», «The information is not useful to me to understand my condition» and «Other» (*Fig. 4*).

This suggest us that PIMs contents had been well expressed and organized in an understandable way.

89% of patients found that booklet was very useful giving a score from 8 to 10 pt., 7% gave 7 pt. and only 4% less than 6 pt.

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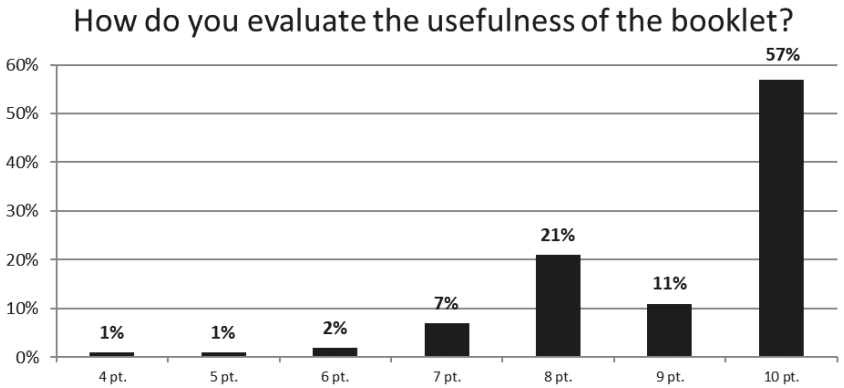

Figure 4. – Booklet usefulness.

The images analysis showed that under no circumstances the examined brochures reach 40 pt. of Gulpease index (*Tab. 1*).

Table 1. – Results.

	Images	Font	Text size	Phone numbers	email	Gulpease index	Negations in the text	Number of pages
Patients undergoing inguinal hernioplasty	21	Helvetica	9	2	1	24	5	2
Patients undergoing eye surgery	18	Helvetica	9	1	1	36	3	2
Patients undergoing chemotherapy	4	Helvetica	9	1	1	32	23	12
Bariatric surgery	18	Helvetica	9	1	1	37	19	25
Knee prosthesis	25	Helvetica	9	1	1	34	3	9

This means that they are not easy to be read by patients with a primary education and middle school diploma (score between 80 and 40) but only by those who have a high school or higher education.

In all the brochures there were at least 2 ways to contact the health professionals (email and/or telephone number).

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We also evaluated the use of «linguistics negations» (like: no, though, but, not, etc.) because human brain does not process negations (Kaup, 2005; Liuzza, 2012).

We also evaluated the size of the institutional font. Someone wrote us that it was too small so we enlarged the font by 9 pt. to 10 pt. making documents more readable even for the elderly.

4. Discussion

In order for PIMs to be effective, they must be «noticed, read, understood, believed and remembered». Patient-centered, balanced education materials at an appropriate level for the reader should facilitate optimal understanding of the deprescribing process, support shared decision making, and ultimately improve health outcomes (Fajardo, 2019).

Advice to improve PIMs advocates the use of plain everyday Italian, written in short sentences, and advises about font, style, layout and format – each of these is likely to affect readability, but is harder to objectively assess (Duman, 2003). The use of pictures, diagrams and space help the reader to clearly see the message within the PIMs (Duman, 2003).

The information provided should be up to date and patients and caregivers should be involved in their construction (Duman, 2003).

Previous studies and literature on readability have suggested different methods of improving readability (Badarudeen, 2010; Yi, 2013). Above all, considering the reading skills of the target population is essential when preparing patient education materials. We have to consider the reader's point of view. We have to replace complex medical terms and jargon with simpler words (e.g., substituting the 12-syllable medical jargon «esophagogastroduodenoscopy» with the commonly understood and 4-syllable word «gastroscopy») and simplifying sentences to be more succinct and easier to understand.

In addition, simpler formatting of text and the inclusion of diagrams, charts, graphs, illustrations and other non-textual figures may also help to decrease the written grade level of web sites (Doak, 1996). Finally, screening education materials and revising them to meet readability guidelines before making them available for patient use may also help in improving readability.

We decided to use the Gulpease index because the two most common methods of assessing the readability and comprehension are the «Flesch Reading Ease» and the «Flesch-Kincaid grade level» (Farr, 1951; Kincaid,

1975). But these two scales use word and sentence length (with different weighting factors) in formulae to provide a score of readability and education level – by the «United States (US) grade level» – of a piece of text (Farr, 1951; Kincaid, 1975). These methods have excellent reproducibility and a high correlation to other readability scales in the United States but we needed to use something related to the Italian language (as the Gulpease index).

The Gulpease index, is the first readability index calibrated directly on the Italian language. It has also the advantage of calculating the length of words in letters, and not in syllables as for the Flesch index.

Even with the simplification of the length expressed in letters, the automatic calculation of a readability formula presents many difficulties, essentially due to the blindness of the computer with respect to the content of the text.

Punctuation is also critical: to calculate the length of sentences, it is necessary to establish where each sentence begins and ends, but on the other hand, in many cases it is not trivial to define which is the last word of the sentence (just think of the multiple uses of the period).

5. Critical issues

We encountered some critical issues in the daily management of patient education materials.

These difficulties are:

- Negotiation with healthcare professionals in order to use simple language in the text, instead of forensic language.
- Distribution of the brochure: involving healthcare professionals not only in writing it, but also in making it accessible to their patients.
- Refueling: it is not easy to keep track of the distribution rate of the brochures and the replenishment of the areas identified as a «self-service» place for collecting the brochure from patients.
- Web availability: creating a paper brochure and not making it available online is a communication failure. This means having to interface with other specialty areas that could slow down the communication process.
- Data analysis: the patient education service is not formalized and is not part of any organization chart and therefore does not meet the data analysis criteria needed to evaluate the impact of PIMs.

6. Conclusions

The education of the adult patient is a transversal area of pedagogy, medical clinic and communication.

Experts from various fields (including patient associations) should collaborate to create informative materials that are useful for both patients and doctors/nurses.

This happens because very often, doctors and nurses, have to explain and re-explain information to patients and caregivers that could easily be read asynchronously (for example at home). In many cases, patients go back to the hospital just to get more information. Sometimes surgeries are postponed because the patient did not do what should have been done to properly prepare, or patients come back for assistance with something they could do alone at home (if well trained) but have not understood how to do it (for example, empty the drains independently).

Primarily, this research is useful to provide tangible data to the Hospital's Management in order to improve the operational path for the creation of increasingly effective brochures.

Furthermore, because this research made possible to direct attention to the pedagogical/training aspect of the doctor/patient relationship rather than only the usefulness of the PIM's for the information's lack of time of doctors or nurses.

7. Practice implications

It is advisable to build the PIMs in collaboration with doctors, nurses, communicators, pedagogues and patient associations. Each one has an added value that will make the final product truly suited to the patient's needs.

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Riassunto

Gli infermieri e i medici della Fondazione Policlinico Universitario Campus Bio-Medico hanno prodotto materiale informativo per i pazienti sotto forma di opuscoli informativi che abbiamo consegnato ai pazienti al fine di aiutarli a comprendere meglio la loro patologia, il percorso terapeutico e la procedura a cui devono sottoporsi. Con il Covid-19, i medici trascorrono necessariamente meno tempo con i pazienti. Ciò significa che i pazienti tendono a (dis)informarsi su Internet in modo maggiore rispetto al passato. Abbiamo analizzato la leggibilità dei testi degli opuscoli con l'indice Gulpease.

Abbiamo sottoposto un questionario qualitativo a 100 pazienti per valutare la chiarezza espositiva, l'efficacia comunicativa e quanto questi consentissero o meno, ai pazienti, di affrontare la loro procedura con maggiore chiarezza e serenità. Le brochure hanno suscitato interesse nel 77% dei pazienti, l'87% ha dichiarato che «I concetti sono chiari e posso capirli», il 55% ha indicato che «L'informazione è utile per comprendere la mia condizione». Nessun opuscolo raggiunge i 40 pt. (base) dell'indice Gulpease. Inoltre, la dimensione del carattere istituzionale è troppo piccola. L'educazione del paziente adulto è un'area trasversale della pedagogia, della clinica medica e della comunicazione. Esperti di vari settori (comprese le associazioni di pazienti) dovrebbero collaborare per creare materiali informativi utili sia per i pazienti che per i medici/infermieri (per poter informare meglio i propri pazienti).

Parole chiave: Comprensione; Covid-19; Educazione del paziente; Educazione sanitaria; Materiale informativo per il paziente.

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