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Information and Communication Technologies in Long-term and Palliative Care

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Abstract

In the beginning of the 21st century we experienced a paradigm shift between the acute and infectious diseases to the chronic conditions, sustained by the aging of the population. Nevertheless, the education system for health professionals kept the traditional educational models. The main idea of the work here presented is to provide a literature review of the state of the art of information and communication technology (ICT) applied to Long-term and Palliative Care. We conducted an exhaustive investigation from Pubmed and Google Scholar using the Medical Subject Headings (MeSH) terms “information and communication technologies”, “e-Health”, “m-Health” and “long-term care”, “palliative care”. Currently, the existence of a critical mass of Internet users allows quickly diffusion of electronic communication in the medical practice, which translates as a new way to look at the doctor-patient relationship. It is important to define the various ways in which one can establish a doctor-patient communication, ensure the security and confidentiality of the information, create practical and “user friendly” interfaces that can be easily used by patients and ensure universal access to new technologies. Despite the existence of some literature on new information technologies applied to the health context, few papers trace the connection between these same information technologies and long-term and palliative care. We believe that the absence of literature on this theme relates to the emphasis of personal contact in such situations and the lack of quality records. More research is needed on this subject.

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1. Introduction

In the beginning of the 21st century we experienced a paradigm shift from the acute and infectious diseases to the chronic conditions, mainly due to the aging of the population. Nevertheless, the education system for health professionals kept the traditional educational models of the former century that focused in the diagnosis and treatment of acute pathologies. It is needless to say that we urgently need new approaches, technologies, skills and knowledge, to address this new reality [42,45]. In the meanwhile, since the 1960's, new information and communication technologies have emerged in the health context.

The main idea of the work here presented is to provide a literature review of the state of the art of information and communication technology (ICT) applied to Palliative Care. In order to accomplish the review, we conducted an exhaustive investigation from Pubmed and Google Scholar using the MeSH terms “information and communication technologies”, “long-term care” and “palliative care” and then filtered the results by the number of citations made to the paper.

2. Theoretical Background

In the beginning of the 21st century we experienced a paradigm shift between the acute and infectious diseases to the chronic illnesses, sustained by the aging of the population. The philosophy currently at practice in medicine is still associated with traditional models based on the diagnosis and treatments of acute conditions, which present themselves as being clearly inefficient. Indeed, the concept of bio-psycho-social patient isn't still a current practice and death is seen as a therapeutic failure instead of being understood as a natural consequence of life itself. [9,20,45]. Despite the fact that acute conditions require specific medical attention, we cannot continue to manage chronic disease in the same way we manage the acute episodes. It is essential to develop an educational model that turns to the chronicity and long-term care, to the disease prevention and to palliative care. [9]

It's also in this context that the doctor-patient communication develops a new and utmost reputation. As said Hall et. al, “medicine is an art whose magic and creative ability have long been recognized as residing in the interpersonal aspects of patient-physician relationship” [7,14,15]. The fundamental objective of any doctor-patient communication is to improve the patient's health and medical care.[4,7] This communication has also evolved throughout the last decades from paternalism to individualism. Information exchange is now considered to be the best model, opening the doors to the current model of shared decision making and patient-centered communication [2,10,17,43]. The workforce is learning to negotiate therapeutic and care plans, to support patients in self-management, to use information systems, and to work as members of multi-disciplinary teams. “(...) understanding the experience of illness from the patient's perspective captures the essence of patient centered care” [27,37]. Health professionals should collaborate among themselves and with patients and their families, in order to develop therapeutic strategies and objectives that focus on their needs, values and preferences [9,26]. There are already some effective means of preventing, treating, and providing palliative care for cancer [29], but are not implemented in most countries (National Cancer Control Programmes: Policies and Managerial Guidelines, 2nd ed. Geneva: World Health Organization, 2002).

It was also in the second half of the 20th century that the new technologies began to develop. As expected, they initially suffered a tough resistance from the health professionals, mainly due to the difficulties it created in the doctor-patient communication [15], as the medical records making process. Currently there are major advances, but there is still the need of some work in order to balance the distribution of this information technologies[4]. As Beaglehole et al. [4] said: “Modern information and communication technologies have positive and negative effects on health”. Besides this, there is still a gap between the information that is sought and the information available on the Internet, either for users and health professionals. In one hand, the demand of information on the Internet is increasing from both sides, in the other hand, its quality is not always validated and when it is, it's not accessible to everyone [38].

“Most healthcare interactions occur in the context of apprehension, anxiety, and time pressure. For a patient worried about the reasons for visiting the hospital and a provider concerned with managing the clinical needs of the patient, any additional activity not considered essential to alleviating their immediate concerns will be unwelcome. This means that even the most basic administrative tasks have more complex dimensions than equivalent tasks in the non-health sector. Add in the complexity of the average patient pathway through the health system, and you begin to understand the challenges faced by anyone implementing a hospital information system” [25]. All experts tend to agree within this framework: face-to-face communication is still the best method to achieve contact between health professionals and the patients, but e-Health tools’ should be seen as a way to achieve the best health care for the patient. [15]

3. Technologies used towards Patient Centered Care

Currently, the existence of a critical mass of Internet users allows quickly diffusion of electronic communication in the medical practice [18,19,41]. The email exchange between patients and doctors provide an important opportunity for communication, increasing patient involvement in supervision and documentation process of their own health, which may even lead to a greater involvement and accountability from the patient’s. This is undoubtedly a new way to look at the doctor-patient relationship, but not everything is positive. Although there are some rules of conduct and ethics at the level of telemedicine technologies and medical software, much of this technology is evolving without this scrutiny, and may increase social disparities (due to some social strata that don’t have access to them) creating barriers on the access of health care [10].

Several ICT applications have been found in palliative care [19,23,34,40] and the “e-hospice” concept is now gaining some reputation [22,24,28]. The most common applications are out-of-hours telephone support, advice services, videoconferencing, consultations and assessments and training and education of health professionals [19].

Thus we found some interesting points that must be developed: defining the several ways in which one can establish a doctor-patient communication utilizing the new technologies, starting on the telephone and building our way through the Internet and the Health information technology, ensuring the security and confidentiality of the information and the issues raised when using these technologies and creating practical and "user friendly" interfaces that can be easily used by patients and ensuring universal access to new technologies.

3.1. Telephone

The introduction of the telephone in the medical practice has gained importance around the time of the First World War and its dissemination occurred with both celebration and concern. On one hand, many doctors appreciated the efficiency and accessibility that it brought, on the other hand, there were many who claimed the disadvantages of the lack of privacy, the overwhelming of patients seeking over-the-telephone care and the risk for misdiagnosis. By the mid-1920’s, the telephone was fully integrated into the medical practice, as it was in the broader society. The telephone had become a mandatory medical technology, as central to practice as the stethoscope and sphygmomanometer [2].

Complex palliative care patients are often home-bound and cared for by family members and domiciliary teams with both doctors and nurses. Personal contact with the palliative care team is not as frequent as desired and is mainly based on clinic or home visits. Thus a communication tool that would allow these patients to be monitored and receive comprehensive care at home is in need [8]. Coyle et. al describe a case report of a 33 year-old patient with an 11-year history of a recurrent brain tumor that has been treated with multidisciplinary therapies. After 18 months of admissions to the hospice, rehabilitation centers, terminal care and long-care facilities, summarizing 16 months as inpatient, he and his family decided that in order to maintain his quality of life, he was going to be cared for by his parents at home. This decision was supported by the palliative care

team that provided 24-hour availability to help problem solve and provide advice, and kept communication, reinforcement and support through daily telephone contacts. During the year of 2000, this patient only had one 5-day hospital admission, exposing one of the benefits of this type of communication.

3.2. Internet

Being on the 21st century we are on the threshold of a vast expansion in communications technology that may have profound effects on the patient-doctor relationship. We are approaching a critical mass of Internet users that will lead us to a wide diffusion of electronic communications within the medical practice. Online, physicians can search the medical literature and find both abstracts and full-text medical journal content. Patients have access to medical information, self-help and support groups, virtual communities [13,16] and sometimes, even medical experts. The "World Wide Web" (WWW) can link patient databases across various institutions. The Internet also allows videoconferencing based on audio-visual communication. In fact, telemedicine services use the Internet and are widely used, especially in rural and geographically distant areas. The use of telehealth can empower patients with chronic and advanced illness and improve symptom monitoring and management by providing a clear and good communication pathway between the patient, and its family and the healthcare providers [19,30,33,44]. At some point in the case reported by Coyle et. al it was hypothesized that besides the daily telephone contacts already transcribed before, regular visual contact between the patient and his supportive care team would enhance communication and decrease the anxiety and isolation experienced by both the patient and his parents. This was even more important in this patients' case due to its hearing loss, hindering the telephone communication. At the end of the 3-month trial period the Pain and Palliative Care team could identify some medical and social benefits such as an improvised and limited physical exam, "curb side" assessment with an attending and the patient's obvious pleasure at visual contact with the clinicians. It was also acknowledged that the opportunity for visual clues for this patient with profound hearing loss improved communication by maintaining and expanding the conversation. This type of communication also led to a cut down on, although didn't eliminate, the need for supportive home visits. It is less comprehensive, but it's more readily available, appears to be less intrusive, and needs less preparation from both parties [12,21].

The last 15 years have witnessed an enormous growth and usage of the Internet. Numerous medical and health related sites are now available, and their numbers continue to grow exponentially. Consequently, a large pool of medical-related information is now available [32]. Essentially, the Internet is made up of several components, each with a different function and format. It allows information to be presented in a sophisticated and attractive format, intertwining text with pictures. New and relatively inexpensive software products have made it possible for users with little computer knowledge and training to browse and utilize it. The reader can access information by simply clicking on highlighted text. The other components include electronic mail (e-mail), news groups, and other smaller networks [10].

The publishing process on the Internet offers several advantages over more traditional publishing methods. Publications can be made instantly available internationally. Updates, revisions, and corrections can be completed rapidly and regularly and editing and printing errors can be corrected with ease at short notice. Electronic publishing decreases the high costs of printing and distributing medical journals - the expenses related to electronic journal publishing on the Internet have been estimated to be 20%–30% of those related to conventional paper publications [32]. Many of these cost savings could be passed onto readers and making subscription fees less costly.

As with many other resources, the Internet too has inherent shortcomings. Some of the qualities that have contributed to the Internet and WWW's growth are also the source of many of its weaknesses. Foremost among these are the ease of publishing. With the exception of a very small number of countries, there are very few legal restrictions on what can be broadcast and retrieved on the Internet. Therefore potential editors and publishers are not hampered by peer-review processes and editorial mechanisms that allow published material to undergo scrutiny and critique by experts prior to publishing. Consequently, there are few controls to

prevent incorrect, out of date, harmful or scientifically unsupported medical information from being published. Sensational anecdotes, which are not uncommon to the Internet, often do not present balanced scientific opinions [38].

Many times, patients and families without the medical training and scientific background required to critically evaluate medical information, seek health-related information on the Internet. This search for health information has various factors such as the greater public interest in health-related issues and the fact that a less-educated group of users are now gaining regular access to the Internet. Clinicians may find themselves being approached and even challenged by patients and their families with misinterpreted information they obtain on the Internet.

Computer skills are only recently being introduced on a large scale to students and clinicians. Training in the use of such technology among medical professionals is still lacking. Software and hardware products and Internet access, although relatively inexpensive in developed countries, may be prohibitively expensive in some developing countries [42].

English appears to be the most dominant language used online. In 1998, 60% of the Internet's host computers reside in the United States. However, not all potential users are literate in English, and this poses a barrier to wider utilization of the Internet [32].

There are numerous applications of the Internet and the WWW that may be useful to palliative care and hospices. The type of information that can be shared is varied: the majority of hospice and palliative care websites describe the organizational structures of their respective programs and provide definitions of Palliative Care and Hospice, which is important to promote these programs and inform the public on services available. Various governmental health departments utilize the Internet to distribute health-related information to the public. Examples of this in North America are the United States National Institute of Health, the National Cancer Institute, and the Canadian Department of Health.

The Internet has been used effectively to enhance the education of pre- and postgraduate medical personnel. It offers palliative care and hospice health-care professionals an opportunity to dialogue with one another, about new developments and difficult cases. Most websites allow readers to contact the sites' editors by e-mail, which provides a rapid and inexpensive means of communication. It is a role that needs to be explored further in palliative care.

A number of reputable medical journals have started utilizing the Internet to publish the table of contents, abstracts and/or full-text published articles. Nowadays it is getting more and more frequent to see complete text articles available to the public and/or subscribers. This is a very helpful service because it assists in keeping clinicians, particularly those who do not have easy access to these journals, informed of recent publications.

The Internet offers a platform for on-line grief and bereavement support. Although it may be argued that the Internet is too impersonal to serve this role adequately, there may be some users who prefer this format.

Pereira et al. crave for the creation of websites by reputable palliative care and hospice organizations. These sites should promote evidence-based approaches or link readers to other sites that do. A system of certification of quality websites, as judged by clearly established criteria, could improve the credibility of palliative care-related WWW publishing [32].

3.3. Email

Direct electronic communication between physicians and patients are also evolving, although so far, these are under considerably less scrutiny. E-mail allows users to correspond with one another rapidly and at much lower costs than incurred by more conventional methods such as the telephone or fax machines. News groups allow readers with similar interests to dialogue with each other. E-mail can also connect physicians with patients, increasing the access to care, enhancing patient education, enriching screening programs, and improving adherence to treatment plans [5,32]. The gap between the crucial need for transmitting more information and the relatively few and often brief face-to-face opportunities for communication between

physicians and patients leads to reduced quality of personal encounters that are further diminished by the need for physicians to address administrative issues. Inadequate communication, now more the rule than the exception, leads to increased stress, diminished satisfaction and decreased adherence to therapeutic protocols. Involving patients and physicians through e-mail could increase the participation of patients in the supervision and documentation of their own health care, processes that may stimulate patients and contribute to improved health [5,35]. For example, the patient may use e-mail to make an appointment. He may request general information, such as quality web sites about his disease, or specific information, such as a modified insulin dosage based on home monitoring of glucose levels. On the other hand, physicians might initiate e-mail contact to conduct routine guidance and education (for example, to advise the family on nutritional facts), to remind a patient of an upcoming visit, or to check on a patient's progress (for example, pain and other symptoms control). In contrast, the use of e-mail might be contraindicated in some situations such as urgent situations, which need to be addressed quickly, to communicate abnormal or confusing test results or to relay bad news [36]. The diagnosis of a new problem requiring a complex and dynamic dialogue might be best handled with synchronous communication. An example of electronic communication is CHES (Comprehensive Health Enhancement Support System), an interactive computer-based system used to support persons with AIDS and HIV infection [28]. Another example is the professionals' opportunity to dialogue and confer with one another. Most websites allow readers to contact the sites' editors by e-mail, which provides a rapid and inexpensive means of communication [32].

Barriers to access often arise simply because physicians can be difficult to reach. Unlike telephone conversations, which require both parties to be available at the same time, e-mail, like voice mail, is an asynchronous mode of communication, essentially creating continuous access to the health care system.

Telephone and voice mail technologies have been effective in screening for mental disorders and substance abuse. For example, computer-generated telephone reminders can improve compliance with preschool immunization visits. "Standard e-mail or e-mail with an interface allowing structured data entry may allow more effective triage and automation of messaging than voicemail" [28].

Whether e-mail between physicians and patients can have advantages for the therapeutic relationship is a question worthy of investigation.

3.4. Health Information Technology (HIT)

Health information technology (HIT) offers various electronic means of collecting, managing, and storing data. By removing the location-specific requirements, the use of HIT for tasks such as databases allows these functions to be performed in diverse healthcare settings ranging from the primary care centers or clinics and hospitals to community-based organizations and patients' homes.

The potential benefits of HIT cannot be fulfilled without the development of user-centered designs (UCD) that feature clinically valuable, intuitive, empowering tools, and that produce reliable, secure, interoperable data. "Patient Centered Design (PCD) is a particular type of UCD where the end-user is a patient that will use a healthcare solution that should meet his/her expectations" [39]. To exert maximal impact on healthcare quality and outcomes, UCD must span the range of care, from wellness and preventative care to diagnosis and treatment, through prognosis statement, chronic illness, and end-of-life care.

Attention to the human-factor aspects of the HIT system may be especially important in palliative care because of its inherently multi-faceted nature (encompassing symptom-focused, psychosocial, caregiver, and spiritual care), frequent provision in the home and community, and dependence on multidisciplinary teams. Just as HIT systems are being developed to support various primary and subspecialty areas of health care, it is also critical to develop discipline-specific HIT systems for palliative care.

Several distinguishing features of palliative care are relevant when considering HIT-enabled data collection [22]. First, palliative care is provided in diverse settings ranging from inpatient and dedicated hospital units to outpatient programs, community-based institutions, and homes. Continuity is often lacking as patients transition across settings. Second, palliative care typically involves a multidisciplinary set of skills

and is provided by care teams comprised of several specialists including physicians, nurses, social workers, psychologists, nutritionists and chaplains. Third, palliative care has emphasized data collection and data quality less than have other medical area. And fourth, the data to be collected focus on quality of life, symptom control, functionality, psychological and interpersonal concerns, and end-of-life planning – elements that are not well codified.

“Historically, hospice and palliative care programs have not been oriented toward research, have not quantified and benchmarked their services, and have not invested heavily in infrastructure for data management. Focused on provision of service in the community, they have had little interaction with traditional quality and research activities; this gap reduces the chance that high-quality data are routinely used to inform best practice” [1].

3.5. m-Health Technologies

Another big step in the ICT were m-Health technologies that use mobile electronic such as mobile phones, PDA's and tablets to support the healthcare professionals with clinical decision systems and data collection tools [1,2,24,35]. The traditional model of episodic care in clinic and hospital-based settings is suboptimal for the management of chronic diseases. Mobile communication devices, in conjunction with Internet and social media, present opportunities to enhance disease prevention and management by extending health interventions beyond the reach of traditional care [11]. The current use of m-health technologies include mobile phone text messaging to warn the patient for an upcoming consultation, or to support management of diabetes, hypertension, smoking cessation [3,6,12,35].

Mobile communication technologies have a number of key features that give them an advantage over other information and communication technologies. The ability to keep a wireless connection delivers the potential for continuous, simultaneous and interactive communication from any location; the devices are portable, small sized, low weighted and rechargeable, but have enough computing power to support multimedia software applications [35].

Many studies have recently been conducted targeting the m-Health technologies, but fewer have been made in the setting of Long-term and Palliative Care. This must be a very interesting area for more studies and developments.

3.6. Issues raised from using technology

Technologies should complement and enhance service delivery and never impose themselves as an extra burden on already work overloaded health professionals. One problem relates to the translation of free-text notes into computer structure and understandable codes. In many settings, physician notes are stored in computers via dictation and transcription, and possibly all notes in the future will eventually be inputted orally. The question arising is how will we convert this text information into computer coding. One solution is the option of the physician coding his/her own data as they enter it through selection menus and other techniques. Entering structured data requires more user time than the entry of free-text information requiring the user to use the same computer's concepts and search for the “right” computer code or terms.

The second problem is that the data provided by the physician's notes isn't the one that managers and outcomes analysts would like to have (e.g., formal function status and detailed guideline criteria). There already are many validated survey instruments for some subject matter (e.g., alcoholism, Depression), but we lack them for many subjects and for much of specialized clinical care. Another problem is that open-entry questions are more symptom/situation oriented than checklist symptom questionnaires, which may have too many irrelevant symptoms. It is difficult to know how to interpret this dichotomy. Furthermore there are differences between patient-completed and provider-completed (and filtered) questionnaires [31].

Unbalanced distribution of a new technology may widen social disparities in health care access and outcomes. Health status outcomes may diverge between different segments of the population due to

differential access on effective therapy, according to socioeconomic or ethnical characteristics. Although Internet access is tilted toward wealthier and more educated users, market forces, enterprises and organizations may structure a substantially more equitable distribution. Such businesses as telephone companies, cable television providers, technology companies, and mass media organizations have identified this vast market for information as a major area for investment and development and web-browsing technology soon will be installed into standard televisions. Mandl et al. [28] state that “medicine will need to adapt the technology, not create it”. Medical software enterprises who develop medical communication should research and monitor rates of access within their diverse patient populations. Studies of cost-effectiveness should establish the medical and economic benefits of information technologies such as the e-mail communication. Enhancement of interface designs must be continuous in order to reduce complex and poorly designed user interfaces that require a high reading level, which could eventually cut off whole segments of the population. Integration of voice and video files into e-mail systems has improved access for patients who are not literate, or are eye or ear impaired.

In addition, if widespread access is to be promoted, the technology must be used wisely. A tend to global access can be achieved if the software to communicate with a health system or physician is accessible from any Internet-connected device. Conversely, access will be diminished if patients are required to have specialized software on a local hard drive or a proprietary e-mail account [28].

4. Critical Reflection

The reformulation of the National Health System (NHS) where time boxed appointments are becoming shorter and more widely spaced, plus the health records’ bureaucratization (examinations, certificates of temporary disability insurance, referrals...) yield to an inadequate information sharing between the doctor and his patient in what is usually considered the cornerstone of the communication - the appointment. This increases stress and decreases patient satisfaction and might also lead to a significant decrease in the therapeutic adherence. Email, as a new method of communication, does not replace face to face communication, but can help address many of the existing gaps of the current system, allowing the doctor to monitor the patient remotely, and instill in the patient the responsibility for his own therapeutic process. Patients can use emails when the information was not clarified in the appointment: "low salt diet - but what is the list of foods I can eat?" or "perform physical exercise – how many sets, how often per week and duration?" and even to schedule an appointment. On the other hand, professionals can use emails in order to consolidate ideas that were discussed in the appointment, to send documents about a particular disease and offer therapeutic’ options, to monitor the progress of a patient or even to recall the date of an appointment.

Our work regards the framework of chronic diseases and terminally-ill patients, since in emergency situations and acute pathologies, using the telephone or direct contact should be the first approach.

Another problem arises upon the need to communicate a diagnosis or laboratory results that changed. This should never be held in deferred and not even by phone. In these cases, a face consultation should always be conducted, but, as it was already mentioned above, more valid and pressing information can be sent through email.

Regarding clinical health records, they support information sharing and reduce the misinterpretation of manuscripts that can be even more damaging than negligence. Currently, this clinical health records system is widespread, and only occasionally finds some resistance from health professionals. There are some methods that reduce the negative impact of its usage in an appointment: rotate the screen toward the patient in order to show him the information that is being recorded; present tables and graphs/charts in order to be able to discuss the evolution of a given parameter, e.g. arterial tension, or simply use the "open issues" of the last appointment to start the current contact. Unfortunately, a secure data sharing or integration between the existing systems (primary health care, secondary health care and palliative care databases) is still unavailable. Often, it is necessary to resort to manual holders for the information to assure that it arrives in a timely manner to the different care providers.

With the growth of an informed and computerized population where Google replaces encyclopedias, many times we (doctors) are faced with questions for which we have no answers. There is a lot of misinformation available that often hinders our work, as doctors, and we have to equip ourselves, whenever possible, with a set of official pages in order to provide reliable information to our patients.

As far as the unequal access to health care services for parties who do not have access to current information technology - Internet, it's a visible issue given the number of available slots for appointments for each physician that can only be booked via Internet. All patients that do not have direct access to the Internet are at a clear disadvantage. This disadvantage is being overcome by the spread of information technologies at lower prices to a larger portion of the population. Health professionals, via pamphlets, meetings, lectures and clear explanations at every visit and appointment, should instruct the population that does not have access to this technology.

5. Conclusions

Despite the existence of some literature on new information technologies applied to the health context, few papers trace the connection between these same information technologies and long-term and palliative care.

It is true that the advent of new information technologies appears to shift the paradigm between acute and chronic diseases. It is rather obvious that if there was already a need for records of clinical acute situations, it is desirable and a need to have records of chronic conditions that need constant monitoring and periodic evaluations.

We believe that the absence of literature on this theme applied to palliative care relates to the fact of the emphasis of personal contact in such situations. One should develop a relationship with the patient and engage in a highly personal contact while dealing with such situations. A chronic oncological patient must know his situation. A way to effectively communicate with these patients is to provide quality information, accessible to the general community. This often helps to decrease the levels of anxiety and facilitates therapeutic adherence that should always be settled between the doctor and the patient. Whenever possible, or desirable for the patient, the progress can be followed at a distance by the doctor, making use of tools like cell phones, e-mail or videoconference to establish the needed contact.

The area of information and communication technologies has a fast pace evolution. On one hand, there is a huge amount of advantages, but, on the other hand, it is necessary to regulate its usage to validate the information that is shared, ensuring confidentiality and respect for patient values, which underpin the doctor-patient relationship.

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