Thesis

Patient Empowerment in Radiology

submitted by

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Declaration of Academic Integrity

I hereby confirm that the present diploma thesis is the result of my own independent scholarly work. I also confirm that in all cases, where material from the work of others (in books, articles, essays, dissertations, and on the internet) is acknowledged, quotations and paraphrases are clearly indicated. No material other than that cited in the reference list has been used. I have read and understood the Medical University’s regulations and procedures concerning plagiarism.

Graz, 10.09.2023 Wolfgang Schwarz m.p.

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Abbreviations

AI	Artificial Intelligence
COVID-19	Coronavirus disease 19
CT	Computed Tomography
DL	Deep Learning
ELGA	Elektronische Gesundheitsakte (an EHR)
EHR	Electronic Health Records
ER	Emergency Room
HLOC	Health Locus of Control
ICT	Information and Computing Technologies
LKH	Landeskrankenhaus (tertiary hospital)
LTC	Long Term Condition
MRI	Magnetic Resonance Imaging
NLP	Natural Language Processing
PE	Patient Empowerment
SDM	Shared Decision Making

Abstract

Patient Empowerment (PE), the concept of giving patients the capacity and power to act on their own health, has gained significance in medicine in the last decade. Since patients are getting older and seem to be willing to actively participate in their own health issues, and time demands are becoming more difficult for physicians to manage, the need for methods to reduce physicians' workload and distribute responsibility among patients is increasing. To improve PE knowledge and competencies must be built on the patient side, dialogue and involvement must take place at institutional and political levels. Through that, time and money can be saved to the healthcare-system while clinical outcomes and satisfaction of patients can be improved. One important aspect in educating patients is targeting resources on patients' level of health literacy. Often patient reports include a number of, for medical lay-people, hardly understandable terms, which leave patients uninformed and disempowered, as they are dependent on further explanation from professionals. To respond to this problem, the potential of artificial intelligence (AI) to simplify difficult-to-understand reports is analyzed in this paper. Patients were given reports in two different formats, the usual format with medical language and a simplified and more structured one. Five different patient reports, with differently concerning results and difficulty were used. Levels of understanding and levels of concern were evaluated. Levels of understanding show a significant increase among all patient reports, levels of concern show a significant decrease when analyzing the reports together. Individually evaluated, in 3 out of 5 patient reports the simplification results in a significant decrease of concern. Interpreting the results, it seems that the translation leads to significant improvements in levels of understanding across all patient reports. Best understandable were short patient reports with fewer and easier translations. Regarding levels of concern, two effects seem to play a role. When patients understand the report, levels of concern are decreasing while depending on the results of the examination, if it was rather alarming or calming, the level of concern becomes more appropriate. With the involvement of electronic health records (EHRs), AI- based text-simplification can improve PE and add value to the healthcare-system.

Zusammenfassung

Patient Empowerment (PE), das Konzept, Patient*innen Kompetenzen und Einfluss teil werden zu lassen, selbst ihre Gesundheit zu verbessern, hat im letzten Jahrzehnt in der Medizin stark an Bedeutung gewonnen. Da die Patient*innen immer älter werden und bereit zu sein scheinen, sich aktiv an ihren eigenen Gesundheitsfragen zu beteiligen, und die zeitlichen Anforderungen für die Ärzt*innen immer schwieriger zu bewältigen sind, steigt der Bedarf an Methoden, die Arbeitsbelastung der Ärzt*innen zu verringern und Patient*innen in ihre Therapie miteinzubeziehen. Um PE zu verbessern, müssen Wissen und Kompetenzen auf der Patient*innen-Seite aufgebaut werden, und es muss ein Dialog und eine Beteiligung auf institutioneller und politischer Ebene stattfinden. Dadurch können Zeit und Geld für das Gesundheitssystem eingespart und gleichzeitig die klinischen Ergebnisse und die Zufriedenheit der Patient*innen verbessert werden. Ein wichtiger Aspekt bei der Verbesserung der Gesundheitskompetenz der Patient*innen ist die Anpassung von aufklärenden Ressourcen an das jeweilige Niveau von Gesundheitsverständnis. Häufig enthalten Befundtexte eine Reihe von für medizinische Lai*innen kaum verständlichen Begriffen, die die Patient*innen uninformiert und entmündigt zurücklassen, da sie auf weitere Erklärungen von medizinischem Fachpersonal angewiesen sind.

Um auf dieses Problem zu reagieren, wird in dieser Arbeit das Potenzial von künstlicher Intelligenz (KI) zur Vereinfachung schwer verständlicher Befunde analysiert. Den Patient*innen wurden Befundtexte in zwei verschiedenen Formaten vorgelegt, dem üblichen Format mit medizinischer Sprache und einem vereinfachten und einheitlich strukturierten Format. Es wurden fünf verschiedene Befundtexte mit unterschiedlichen Ergebnissen und Schwierigkeitsgraden verwendet.

Der Grad des Verständnisses und der Grad der Besorgnis wurden bewertet. Der Grad des Verständnisses steigt bei allen vereinfachten Befundtexten signifikant an, der Grad der Besorgnis sinkt signifikant, wenn die unterschiedlichen Befunde zusammen analysiert werden. Einzeln ausgewertet führt die Vereinfachung bei 3 von 5 Befundtexten zu einer signifikanten Abnahme der Besorgnis.

Die Interpretation der Ergebnisse zeigt, dass die Übersetzung zu einer signifikanten Verbesserung des Verständnisses bei allen Befundtexten führt. Am besten verständlich waren kurze Befundtexte mit weniger und einfacheren Übersetzungen. Hinsichtlich der Besorgnis scheinen zwei Effekte eine Rolle zu spielen. Wenn die Patient*innen den Befund verstehen, sinkt der Grad der Besorgnis, während der Grad der Besorgnis je nach den Ergebnissen der Untersuchung, ob sie eher alarmierend oder beruhigend war, angemessener wird. Mit der Einbeziehung elektronischer Gesundheitsakten (wie zum Beispiel die ELGA) kann KI-gestützte Textvereinfachung einen wertvollen Beitrag zu Verbesserung von PE und einen Mehrwert für das Gesundheitssystem schaffen.

1 Introduction

1.1 Defining Patient Empowerment

The wide concept of Patient Empowerment (PE) is difficult to define due to a lack of clarity surrounding its true meaning. There are numerous definitions that can be found in the literature. They differ in focusing on interventions aimed at promoting PE, the transformative process of patients as they become empowered or discussing the background of PE, as a part of self-determination theory (SDT) for example. [1] Generally speaking, PE can, without the claim to completeness, be described as all actions from patients and health care providers aiming at giving patients capacities and abilities to take an active role in educational interests, decision making and management of their own disease, with the goal of improving important patient related outcomes. While this brief definition of Patient Empowerment is incomplete and does not capture the full scope of the concept, it emphasizes the patient´s point of view.

One often cited definition of patient empowerment was made by Funnell et al. He describes the process of empowerment as *“the discovery and development of one’s inherent capacity to be responsible for one’s own life. People are empowered when they have sufficient knowledge to make rationale decisions, sufficient control and resources to implement their decisions, and sufficient experience to evaluate the effectiveness of their decisions. Empowerment is more than an intervention or strategy to help people make behaviour changes to adhere to a treatment plan. Fundamentally, patient empowerment is an outcome. Patients are empowered when they have knowledge, skills, attitudes, and self-awareness necessary to influence their own behaviour and that of others in order to improve the quality of their lives.” [2]*

This definition provides a more complete and nuanced view of Patient Empowerment.

1.2 Related concepts

The unclarity in defining PE in the past has led to the emerge of many related concepts of PE, that need to be briefly discussed, before diving deeper into the matter of PE. These concepts have similar interests and overlapping issues but none of them can be used interchangeable to PE, since the concept of Patient Empowerment is a lot wider than each of them. [3] They are being shortly discussed because research often focused on only one of these sub-concepts, as part of PE, and in this paper, they all are being discussed as part of the whole concept of Patient Empowerment.

Related concepts include patient centeredness, patient participation, [3] patient activation, patient engagement [4, 5] or patient enablement and perceived control [4]. Key concepts of PE include self-management, shared decision making, health literacy and self-efficiency, which will be discussed separately.

Patient centeredness describes focusing the health care decisions on the patient and his/her needs, demands and preferences. The patient is seen as the main customer in medical services and his opinions and values guide medical decision in a strong way.

Involving the patient into decision making and tailoring treatment plans according to the patients are key features. [6]

Patient participation can be seen as a pre-condition for patient empowerment. It describes, that the patient is taking an active role in decision making and disease management, away from a paternalistic view of medicine to a more collaborative approach. Patient participation is something patients need to do independently. Health care providers can only facilitate the process through actively communicating with patients and coaching them to develop changing skills and self-confidence. [3]

Patient enablement describes the level at which the patient is capable of taking good decisions regarding their own health. It focuses on patient's capacity and behavior, and their abilities to cope with their own health issues. Enabled patients do not necessarily have the motivation and power to act on their interests. [4]

Patient activation means, that patients have the abilities and also the necessary motivation to manage their own health issues. Patients need the necessary knowledge, skills and confidence to understand their role in the health care process to be activated. [4]

Patient engagement describes that patients are taking actions, which have a positive effect on their own health and well-being, to get the most out of their situation. It also describes that patients use all resources that they are given by the health care system, being educational or therapeutic. It also assumes patients have the necessary capacities and skills in order to take these actions. [4]

A patient's **perceived control** in health plays an important role in patient empowerment. What patients believe in and what they think can influence their health has a strong impact on their outcomes. The health locus of control (HLOC), which is the belief in what really influences a person's health, is influencing the extent to which patients adhere to a medication for example. Positive beliefs of HLOC are intrinsic, or doctor´s health HLOC. Negatively associated control beliefs are for example chance, god or powerful others HLOC. [7] [4]

Self-management and shared decision making are more a method in leading to a more empowered patient. They will be discussed in another section.

Health literacy is the key outcome of educational programs for patients. It will be discussed thoroughly in the following. **Self-efficiency** as well is an important outcome of empowered patients. Its importance is especially underlined in self-management of chronic diseases.

1.3 Levels of Patient Empowerment

All of the listed concepts are aimed at strengthening the patient's role in the treatment process. Patient empowerment is seen as the most holistic term of this selection. For better readability and understanding this paper will be focusing on this term in the following. [4]

Patient empowerment, and strategies to promote the progress of initiatives can take place at three different levels, which are all interdependent: the microlevel, the mesolevel and the macrolevel.

In the **microlevel**, the factors that indicate patient empowerment are individual characteristics by either the patient or the health care provider. Patient characteristics that play a role at the microlevel of patient empowerment are for example personal characteristic, beliefs and attitudes, self-efficiency and literacy levels. From the providers side of view, also personal characteristic and attitudes play a big role, as well as communicational skills and professional goals. [1]

The **mesolevel** describes patient empowerment on institutional level. At the mesolevel, for example, the setting of patient contacts, the use of shared decision making (SDM), motivational interviewing or time taken for one patient can be seen as indicators of PE. Personal training interventions and health coaching are effective strategies that can improve PE at the mesolevel. [1]

The **macrolevel** describes the health care system level. Important indicators of the macrolevel include the law aimed at patient inclusion, the political context, advocacy groups, and how much patients and patient initiatives can influence health care. There can be a positive influence on health outcomes when patients with long term conditions (LTC) are given support in self-management or there is patient inclusion in decision making and legislation surrounding healthcare. Support of patients with long term conditions (LTC) to self-management or inclusion of patients in decision making and legislation in health care questions can positively influence health care outcomes. Possible interventions at the macrolevel include educational programs or self-management programs for clinicians and/or patients. [1]

1.4 History of patient empowerment

The root of the movement towards patient empowerment was started in social action movements, to help suppressed groups, such as minorities, poor, working class residents and women towards more inclusion, power and autonomy. The concept furthermore gained size during the 1960s civil right movement, which was more focusing on emphasizing the abilities and rights of those groups rather than focusing on the needs and deficits. During the self-help movement in the 1970s/1980s the concept was furtherly embraced and gained importance. In the following three decades political decisions and legislation led to another rise in importance and recognition of patient empowerment. International attention was growing and many super-national Organizations, like the World Health Organization (WHO), formed guidelines marking the importance of patient centeredness, information and empowerment in health care services. The main focus lays on assisting people in gaining control over their own diseases and its management. Individual factors are as well as community factors strongly included. [3, 8-10]

1.5 Relevance of Patient empowerment

In the past, medical decisions have been made solely by the doctor for the patient. This paternalistic view of decision making in medicine is changing. Since information accessibility and overall literacy is rising, patients want to participate in medical decisions as well. This is not only a desire from patients, it can also be seen as a big opportunity for health care professionals as alluded to in the following examples. [1]

Especially in the care of long-term conditions (LTC), the concept of patient empowerment has shown its clinical significance. Patients can be educated to monitor themselves and presentations to the ER can be reduced. [11] HbA1c in patients suffering from diabetes can be lowered significantly with correct self-management and complications thereof can be avoided. [12] Back pain can be reduced by educating patients about their disease and walking them through adapting to it. [13]

Modern diagnostic technology has somewhat made communication with patients of lesser importance when compared to finding the correct diagnosis. [14] The exact opposite is true when it comes making decisions regarding treatment for patients. The rising number of treatment options for diseases has led to a rise in the importance of tailoring therapy options to the preferences of patients. It is important to recognize that patients do not always want the same therapy as what the doctor may think is best for the patient. There is a strong need of not only diagnosing the disease but also performing a correct preference diagnosis to find the best treatment for patients. [14]

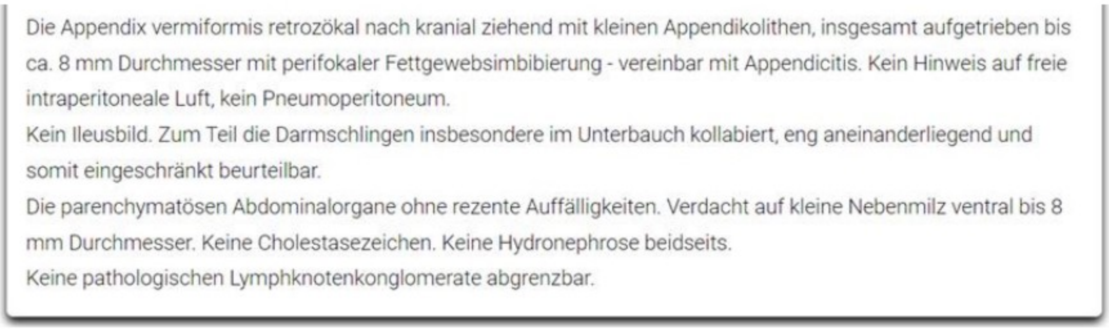
As people are getting older and demands on the health care professionals time is rising, there is a need for a concept to distribute management and health responsibility. Through empowering patients, one can save both time and money in the health care system while clinical outcomes and quality of life can be simultaneously improved for patients. [15]

Mentioned above are just a few positive effects of patient empowerment. An implementation of this principle in modern healthcare will undoubtedly bring about a positive change for both patient and healthcare professional. There are, however, some barriers that will make this process challenging. The medical field can be overwhelming for patients, filled with complicated clinical terminology and a deluge of information lets, patients may often find themselves confused when being confronted by the system. [16] The aim of this paper is to discuss what patient empowerment is and which aspects are important for its implementation, but also which barriers there are. We are also discussing one specific method in empowering patients through education. We are developing an AI-based patient tailored text transforming software which will help patients to participate in their health care decisions. We highlight the importance of patient education through tailored text to their literacy levels, as an important aspect in patient education.

1.5.1 Focus AI-based text simplification

In this paper we will focus on one possible aspect of patient empowerment, namely text simplification of patient reports, by using artificial intelligence (AI), especially in the radiologic setting. The paper is part of the project **simplifAI**, aiming at automatically translating medical texts from all fields into easy-to-understand patient-centered versions.

Every time a patient visits a hospital or consults the primary care physician, radiologist or other medical specialists, the present complaint or symptomatology is documented and the course of examinations and treatment is summarized in a document – the patient report. This document is used by the physician to document the current status of the patient as well as to exchange information between physicians involved in the patient's care. Inherently, the patient report is written in medical terminology that is difficult to understand by a medical lay-person (see Figure 1). Patient discussions at the time of diagnosis often overwhelm patients and sometimes many days pass before the next doctor's consultation. From the point of view of an emancipated patient who assumes responsibility for his or her illness on an equal footing with the attending physician, this is an unsatisfactory state of affairs.



Die Appendix vermiformis retrozökal nach kranial ziehend mit kleinen Appendikolithen, insgesamt aufgetrieben bis ca. 8 mm Durchmesser mit perifokaler Fettgewebsimbibierung - vereinbar mit Appendicitis. Kein Hinweis auf freie intraperitoneale Luft, kein Pneumoperitoneum.

Kein Ileusbild. Zum Teil die Darmschlingen insbesondere im Unterbauch kollabiert, eng aneinanderliegend und somit eingeschränkt beurteilbar.

Die parenchymatösen Abdominalorgane ohne rezente Auffälligkeiten. Verdacht auf kleine Nebenmilz ventral bis 8 mm Durchmesser. Keine Cholestasezeichen. Keine Hydronephrose beidseits.

Keine pathologischen Lymphknotenkonglomerate abgrenzbar.

Figure 1: example of a text passage in a typical patient report. This paragraph contains 18 medical terms and is hardly understandable for medical lay-people

Comprehensible patient reports have the potential to benefit patients and physicians in different ways. Studies demonstrated that patients who understand their disease processes are more likely to adhere to treatment plans and have better outcomes. [17] For clinicians, report simplification provides aid for patient discussions and can help make conversations more efficient.

The availability of electronic health records (EHR) and the advent of Deep Learning (DL) technologies in natural language processing (NLP) now enable a semantic analysis to translate relevant content into language that medical laypeople can understand. This method of translating medical language into a more simplified and easier to understand patient report is time effective and can be used above the scope of radiological text simplification onto various fields of medicine in the near future.

In the research section of this paper we will discuss the positive effects of simplified patient reports on patients understanding and levels of concern, through a study, performed at the LKH-Graz, in Austria.

1.6 Indicators of Patient empowerment

The two most important indicators of patient empowerment are patients´ capacities and patients´ activity. These two indicators can be used to define patient´s level of patient empowerment. [1]

One the one hand, patient capacity describes patient’s knowledge, attitude and resources regarding medical topics. **Health literacy** is an important keyword in this context.

Improving health literacy is the desired outcome of most educational programs and medical communication, since it improves not only adherence to treatment regimens [18] but also positively influences overall health. [19] It is strongly linked to general literacy in a population. Health literacy not only describes how much patients know about their disease. It generally consists of three levels:

- **Functional health literacy:** The basic form of health literacy, where information about medical topics is gained by a population without interactive communication. Examples would be educational written pamphlets or media resources. Outcomes are improved knowledge, compliance and higher participation in vaccination programs for example. Older educational programs mainly focused on improving functional health literacy. [19]
- **Interactive health literacy**: The second level of health literacy is meant to improve abilities of deriving meaning from different sources of information and to apply it to changing circumstances. Outcomes like social skills are developed and participation is improved through higher self-confidence and internal motivation. Examples of interventions would be self-help groups and patient tailored health communication. [19]
- **Critical health literacy:** the third and highest level of health literacy focuses on integrating and critically analyzing information about medical topics. Critical health literacy not only improves individual outcomes, it also strongly linked to community outcomes, by addressing social and politic structures to improve, for example, environmental, social and economic factors contributing to health in a population. Effective methods can be advocacy communication to politicians as well as other important stakeholders or facilitating community action. Personal and community empowerment are both goals of critical health literacy. [19]

The outcomes of health literacy should not only be in improving patients´ knowledge, awareness, participation and health promotion. But it should also influence other determinants of health, namely such as environmental, social and economic, which will in turn have a major impact on the population's overall health. [19]

Self-efficiency is another keyword of patients´ capacity. In short, it speaks to how confident a person is, that he/she is able to adapt to new circumstances and to implement a new action for themselves. The importance of self-efficiency will be pointed out in the section of self-management and self-efficiency in this paper. Personal attitude towards health and perceived control are also important indicators of patients capacity. [20]

Patients´ activity on the other hand is the second defining factor of the level of patient empowerment. It describes all actions from patients that lead to a higher level of participation. Shared decision making between patient and doctor, disease-self-management and taking part in collective activities as well as continuously self-informing are important patient´s activities. [1]

These topics will be discussed in detail in the following section. Important methods on improving the most important indicators of patient empowerment will be discussed as well.

1.6.1 Education

As already pointed out, patient education is an important method in empowering patients. One main focus of patient education is increasing patients' knowledge and overall health literacy. There are various ways of educating patients with medical topics. This paper will only focus on the most important and relevant aspects of patient education, since a complete list will be quite exhaustive.

The most important methods of patient education are verbal communication, written leaflets, electronic resources, group education and physical demonstration. Each one of these methods have their advantages and disadvantages, as discussed below.

Educational programs are aimed at improving health literacy. As previously mentioned, one part of health literacy is the patient´s knowledge. Patients´ knowledge is acquired through steps and needs ongoing effort to be improved. The different stages of knowledge improvement, as Gold et al [21] described, are:

- Acquisition, where knowledge is built through search and creation for example
- Conversion, where gained knowledge is being organized, stored and integrated.
- Use and application, where knowledge is being shared and used
- Protection, where knowledge is being stored [6]

All these activities and possible enablers of the different steps are evaluated in knowledge management theory. [6] Different educational methods focus on either one or more of these steps in knowledge improvement and are discussed in the following.

It is important to mention that efficiency and usefulness of each of these methods can vary strongly in different situations and with different patients. The method needs to be tailored to the level of health literacy of one patient, as well as to the willingness of patients to participate in their health care decisions. Important factors of patients´ willingness to learn about their own disease and the effectiveness of education to patients are [22]:

- Acceptance of patient role
- Health literacy
- Age
- Gender
- Socioeconomic background
- Level of education
- Usage of alternative medicine

[22]

No-one should be seen as beyond empowerment, but it is important to recognize that patients in certain situations may not want to be empowered. [23]. Since patient empowerment cannot be achieved without the participation of patients, it is important to recognize that some people in some situations may not want to gain more knowledge about their disease. In these cases, educational methods are deemed to be ineffective. Thus, the important task for health care professionals in the educational context is to facilitate education for patients and not to impose it. [23]

1.6.1.1 Verbal education

One of the most important methods of patient education is through verbal communication. It is important to mention that the amount of information, that can be transferred through verbal communication is limited, due to different factors, such as:

- high literacy discrepancy between patient and doctor. It may often be difficult to find the right vocabular tailored for the patient's needs and their level of literacy
- patient´s capability of remembering information transferred verbally in a short period of time. Patients forget a lot of what they are told when attending doctors' practices due to various reasons, this then leads to less knowledge being taken home with the patient regarding their health. [24]
- Time is an important factor in health care. Since verbal transfer of information is only 1:1, there are more time-effective methods of patient education than verbal.

Although there are a lot of disadvantages of 1:1 communication, the verbal transfer of information remains a very important method of patient education. It is important for patients to feel understood and also to be encouraged to ask questions and share beliefs and concerns for optimal information exchange. An open and respectful communication is the basis of good verbal education. Although time-efficiency is low, the verbal communication between doctors and patient remains one of the most important interactions between doctor and patient. [14]

One important method, which needs to be discussed is the teach-back method in verbal education. After being educated regarding a medical topic, patients are asked to repeat the information given. Patient satisfaction, post discharge readmission rates, disease self-management capability and knowledge can be improved by using the teach back method. [25]

1.6.1.2 Printed education

There are many ways in which printed information can be delivered to a patient. Pamphlets, brochures and educational handouts can provide patients with necessary information regarding their disease and through that, improve their knowledge. One of the most prominent advantages of printed education is that the patient is able to read it whenever he/she wants to and take the time needed to understand the information. This is especially helpful for people with low levels of health literature profit the most from written education. [26]

Time effectiveness for health care providers is given to a larger amount than with verbal communication. Health care providers´ time is not needed for the patient to gather information. Questions regarding the information given in the printed format can be discussed in another appointment.

An important factor, which indicates the effectiveness of these methods is the used language. Information must be tailored to the patients' reading abilities and level of health literacy in order to be effective. Studies show that appropriately tailored printed resources lead to an increased information recall and overall knowledge. [26]

Another factor that defines effectivity in written information is, if the information is tailored to a specific patient. Although not all written information for patients can be tailored to each specific person due to time demands, some can. Information on specific findings of investigations of one patient are always tailored to the patient. Making findings of investigations understandable for patients would provide individual written information that can be seen as written education. Greenfield et al showed that individualized information resulted in better clinical outcomes and preference of more active roles in decision making. [27]

In Austria written information for patients from their health care professionals is often hard to understand as what is printed is doctor-to-doctor communication and not necessarily a patient tailored version. [28] Many patients do not understand their own summaries of hospital stay which leaves them poorly informed. Patients leaving hospital often find themselves poorly informed about their condition and face difficulties understanding summaries of their hospital stay. [29] A patient tailored summary of all the investigations could increase patient understanding and in turn overall health outcomes.

1.6.1.3 Electronic education and communication

Electronic resources are a considerably newer method of information transfer, but the field of use is continuously growing. Electronic health portals can provide patient-to doctor communication as well as independent patient education. Telemedicine is a way that may be used to exchange information between the doctor and patient. The main idea is to exchange medical information between doctor and patient, and to discuss problems even if there is separation in terms of place and time. Telemedicine can be held synchronously, that means via video-chat, or asynchronously. Synchronous telemedicine saves time and traveling costs but it may be inconvenient to the patient and the doctor, due to the need of having a constant and reliable connection to the internet. Asynchronous telemedicine refers to patient information and communication being stored online, both doctor and patient then have access to all this information, at any time.

Another way of electronic information transfer is through modern information and communication technologies (ICTs). There are various ICT tools, a few important ones are listed below. Information and communication can be transferred through social media, E-Mails, SMS, text messages or videos. And the tools are accessible from various devices such as: mobile type devices (e.g. Smartphone) or computing devices (e.g. tablets). The use of ICTs is not only in education and information for the patients, but also in the broader context of tele-management. Tele-management includes, education, self-monitoring, written action plans, setting of goals and regular reviews of medical records. The broader context of the use of ICTs is enhancing patient related positive effects through facilitating communication between doctor and patient, while also allowing them to learn more about their disease. The information gathered via tele-management can also be integrated into electronic health records (EHRs), which would make it easier for both sides to see the current management plans and aims. In a recent review about the effects of these technologies in asthma patients they were shown to improve patient related outcomes (e.g. lung function, quality of life), reduced costs, improved communication, improved medication adherence and improved asthma related knowledge. [30]

One of the most important tasks is to tailor the patient specific information to patient specific health literacy. Many studies show that a big part of the educational information for patients found online is not easy to understand for patients with low health literacy. [31]

This highlights the importance of the abovementioned technologies, and how they may convey information in a patient-tailored language and in turn make for easier readability. Modern technologies, such as artificial intelligence (AI), can help in translating often hard to understand medical texts, to more patient friendly texts. This topic will be thoroughly discussed in the research section of this paper.

1.6.1.4 Group education

Group based educational interventions have shown even better effects than individual educational programs. They have shown high usability as they provide opportunities for patients to learn from each other, share experiences, and build supportive relationships. [12] According to Menon and George 2018 [32] access to communities of chronically ill patients with the same diseases is one of the most effective measures for empowering patients and for promoting disease self-management.

In the context of knowledge development as knowledge management theory describes the **use and application** of knowledge as one of the most important steps. [6] Active communication between health care professionals and members of the group includes the following important levels in knowledge management: knowledge acquisition, conversion and use. This empowers the patients to take daily decisions regarding their chronic illness. [6]

In one study about Diabetes Mellitus Type II (DMT2) and effects of group based educational programs on the HBA1c levels of the patients, the level improved even more than with individual education. The overall costs of group based educational interventions at first seems to be higher than that of individual education, but the cost effectiveness is higher in the long run due to money saved by reducing HbA1c levels and resulting complications. [12]

1.6.1.5 Demonstration

Demonstration as an educational method is very important for patients dealing with chronic diseases, which need to be self-monitored (e.g. DMT2) or treated with practical approaches like dietary adjustments or physiotherapy or. Studies have shown the effectiveness of demonstrating practices in physiotherapy for patients with lower back pain. It was shown to reduce back pain intensity and enhance long-term function. [33] Active demonstration for the use of asthma inhalators for example improves adherence to the therapy. [30]

The relevance of demonstration as a method in patient education is obvious, but it is not always easily applicable. For example, in some situations it might be impractical or impossible to provide hands-on education such as in the case of remote consultations or telemedicine. In these situations, demonstrational videos, written instructions and or interactive simulations can be used. [33] [34]

1.6.2 Shared decision making

Shared decision making (SDM) is an important method in patient education and participation. The method was developed in the 20th century, whilst access to medical information and the ability to acquire tools for researching was growing, as was the desire of autonomy for patients. Over that period, the need of a move away from the paternalistic approach in medicine and a move towards shared decision making in the wider aspect of patient empowerment was born. The aim of the method was to reach the optimal medical decision according to patients' preferences and clinical requirements. Patients are encouraged to deliberately express their preferences leading to active communication between the doctor and patient. [35]

To make SDM possible, some variables are necessary:

- There must be two participants (health care provider/ patient)
- Information is being shared between doctor and patient
- Talking about possible interventions, the aim is consensus
- Initiation of the therapy together

In the often-cited paper by Elwyn et al. there are three steps in establishing shared decision making: Introducing choice, giving option while introducing decisional support to the patients and making a decision-talk where patients are helped to explore their preferences and make a decision. [36]

Introducing choice for the patients is the first step to SDM. Many patients expect the doctor to decide what is best for the patient. The first step is to break this assumption. The doctor is the expert in medical terms and treatment options, but the patient is the expert in living with the disease and on his/her priorities. The patient needs to understand, that there are various treatment options, and there needs to be a consensual decision made on both sides. [14]

Giving option is the second step. When patients accept that they are on "the team" in finding the correct treatment plan, they need to be given the options of treatment. This part is one of the most difficult parts of shared decision making. When explaining options, health care providers not only need to explain possible outcomes and side effects, but also to interpret patients' reactions and preferences and see, if their current preference might be based on wrong assumptions, hopes or fears. It needs good communicational skills by the provider to correctly perform this task. [14] Decision aids might be helpful in this context, as they can help to find the correct preferences of the patient, and this can be time sparing. [37]

In the last step a decision is to be made. Patients might ask for a recommendation or make an informed decision by themselves. If the health care provider is asked to make the decision, it is important to evaluate how confident he/she is to make a preference diagnosis (how confident they are, that they know about the patient's preferences). If not confident enough, further evaluation of patient's preferences is needed. If confidence is given, the diagnosis can be made. If the patients take the decision, it is important to reflect consistency with earlier stated preferences. If the result of the decision is consistent, to what has been said in the decision talk, the health care provider does not need to perform a preference diagnosis anymore, the patient has. If there is inconsistency, possible misunderstandings must be evaluated. [14]

The relevance of decision aids in shared decision making has been outlined by a recent Cochrane Review, which showed, that they improve knowledge of treatment options, improve clarity on what matters most to the patients themselves, improve perceived information, improve accuracy on expected benefits and harms of treatment and that patients are more likely to participate in shared decision making. [37]

Eleanor Roosevelt once said: *“Understanding is a two-way street”*. If performed correctly, shared decision making between doctor and patient is known to promote adherence, which leads to better clinical outcomes, better patient understanding and potential direct positive effects on patient relevant disease outcomes. [36]

1.6.3 Electronic health records

Electronic health records (EHR) are databases, where medical information about a person is saved online and where communication between physicians and patients can take place. Access to some sort of electronic health record is granted by more than 90% of health institutions nowadays. Using electronic health records can improve patient’s knowledge, understanding and participation, it can facilitate communication and appointments. [38, 39]

The use of these portals is still lacking in the medical field, only 15-30% of the population is using them. The most frequently reported barrier to patients is that they cannot easily understand the information that is given. [38] Other important barriers include limited digital skill and confidence, preferences in verbal communication, privacy concerns and desire to give more feedback. [38] Thus, the effectiveness of EHRs is strongly connected to two things: patient centeredness and removing barriers.

Patient centeredness means that the visible data fits the patients´ needs. That means, for example, that patient reports are adapted to the patient’s level of health literacy, so that the patient understands it and can therefore best participate in informed decision-making. Patient centeredness can also be very context-specific, for example patients undergoing magnetic resonance tomography of the prostate would wish their report to include probability of there being cancer. [40] Laboratory data should not only be presented in tabular form but with visual demonstrations, and the language used in report texts should be adapted to a level that patients can understand and include further explanations, if necessary. [38]

The reporting of radiological examinations is of particular importance for patient-centered report texts. This has mainly been done in medical jargon, as communication between physicians, meaning it is oftentimes incomprehensible to most patients. Several problems result from this namely; participation in informed decision-making becomes more difficult, patient satisfaction as well as use of EHRs declines, and incidental findings can fall through the cracks if no other primary care physician is seen after a screening. [41]

Patients have the right to be informed about results of examinations and medical documentation. Access to EHRs is also given to every patient in Austria. For the interpretation and the resulting steps, however, a trained medical professional is often still necessary. [42]

The importance of patient participation and information is well documented. The steps to implementing patient centered electronic health record tools is not easy. It is also important to see the patient, in this context, as a partner with whom a journey is shared, including sharing in the responsibility. Standardized EHRs adapted to the patient's level are the future of radiology reports. [41]

1.6.4 Patient-centered EHRs

The importance of incorporating EHRs to improve PE is hard to dispute. In Austria, the most widely distributed EHR system is called the ELGA (German: elektronische

Gesundheitsakte). ELGA tries to involve patients in their own health, but there is much room for improvement.

EHRs around the world are under continuous change, since different health care systems try out different features and analyze it´s effects. Although, in Austria, access to the ELGA is provided by all public health care institutions and also in many pharmacies and in the private practice sector (BMF), it´s use among patients is not equally high. Besides not everyone using the ELGA, or similar EHRs, there even are 281 thousand general refusals (complete ELGA deregistrations), which corresponds to about 3% of insured individuals, in Austria, mostly due to privacy concerns. [43]

To this date, in 2023, the ELGA offers patient insights to their medical data only in their original format. In their EHR, patients can find the patient report alongside other investigations and laboratory data in their original form. As discussed above, these materials often do not fit the needs of patients regarding health literacy and information needs. This unsatisfactory state of affairs led to continued research into what an optimal EHR system would look like.

But what are features, that have shown positive effect on patients, which could be included in future EHR systems? Studies, that investigated the outcomes of features of patient portals from early adopters, show what EHRs could offer to patients if they were centered to them. In the wider view, EHRs can even be seen as a tool to smoothen workflows in clinical practice and communication between health care personnel and patients.

To make the data, accessible in the EHR, really patient-centered, the following key aspects can be included:

- **Communication:** especially in the in-patient setting, but also in the out-patient setting, patients would profit from being able to communicate with their health care professionals via their EHR-system. Concerns, needs and preferences, as well as update requests, can be made, and coordination and feedback can be facilitated. A big concern of many physicians is the overwhelming number of messages and constant interruptions that an open messaging window could allow. Better, patients can be asked specific relevant questions, in order to have the answers focused on important aspects and to avoid overwhelming communication. Feedback should be facilitated to be given. [44]
- **Giving care plan information**: In the in-patient setting daily schedules, goals, diagnosis list or problem list, expected hospital course and discharge criteria can be made. For the out-patient setting post discharge summaries can supplement paper-based patient reports with instructions, medication lists including educational material about them, purpose and possible side-effects. [44]
- **Clinical data:** Patients can have access to their own laboratory data in a patient centered, graphic, version. Generally, the use of audiovisual material, compared to plain texts, led to higher use rates of the EHR among patients in various studies. [38] Also, medication name, dose, frequency and administration method can be summarized. Viewing clinical notes in the in-patient setting can help patients understand their medication-regimen, build better understanding and prepare for visits. [44]
- **Patient education:** Especially when confronted to medical data, patients would profit from having trustworthy educational resources included in their EHR system

together with their personal results. Ideally, the content is targeted to the patient´s disease as well as to their level of health literacy. Besides that, it should be not so dense with information as would be overwhelming to the patient. Since targeting educational material to patients individually would demand a lot of effort, especially here, artificial intelligences can help by generating it automatically, without the demand of time by a health care professional. [44]

- **Patient generated content**: patient safety concerns regarding medication, hygiene, communication and privacy can also reduce medical error rates and improve care. [44]

By implementing these aspects in the EHR in future, patient acceptance and rates of use can be improved, since content and features are targeted to the patient´s preferences. Another important point in improving use-rates would be to remove barriers in the use of the EHRs. Especially people with low digital and overall literacy suffer from problems using the current EHR systems. Studies, which consisted of personal training for EHR use resulted in higher use rates because digital literacy barriers could be removed. [38]

1.6.5 Self-management

Self-management refers to the state of taking an active role in managing your own health. As Paul Watzlawick once said: *"one cannot not communicate"* , [45] you cannot not manage your own disease. You could not engage in any healthful behavior and also not actively manage your own disease but still it will be a form of disease management. Though not the best.

So, what is the best way to manage one's disease and how do you help patients to manage their disease best possible is an important question. The relevance of this question is especially given in case of chronic diseases, where ongoing management defines health outcomes. Since more and more patients suffer from chronic diseases, compared to earlier times where patients suffered more from acute illnesses needing a doctor, self-management is gaining importance.

As Corbin and Strauss [46] defined a framework for self-management, it has three tasks:

- Medical/behavioral management, which refers to patients taking their medication, doing exercise, inhaler-techniques for asthma patients
- Role management, where patients are taught to develop new healthy behaviors which may positively influence their disease
- Emotional management, where patients are taught, how to adapt to possible negative emotions (e.g. fear, anger). [47]

To achieve these tasks five core skills are of big importance for patients:

1) Problem solving
2) decision making
3) resource utilization
4) forming a doctor patient partnership and
5) taking action.

In summary, it means that patients 1) need to formulate problems and find possible solutions and evaluate the outcomes, 2) need to take decisions on their own about new occurring problems, 3) need to know where to find the information they need, 4) need to see the doctor as a teacher, partner and supervisor over the treatment plan and to 5) take action. [20]

Taking action may be the most important task. In taking action one aspect is of tremendous importance for its outcome: self-efficiency. Basically, self-efficiency means how confident a person is, that he/she will develop a new set of skill or routine. Both baseline high self-efficiency and self-efficiency improvement are associated with improved health outcomes. [48] The best way to improve self-efficiency in a patient is to formulate an action plan. It is important for the action plan to be precise, doable, and connected to confidence of achievement.

This means the patient has to say exactly what he wants to do, for example going for a run on Monday and Wednesday from 1:00 to 2:00 p.m. before lunch. It must be doable for the patient, meaning he/she must be able to run that long, have the right equipment, etc. The patient must be able to say that he is going to achieve the goal with a confidence of 7/10, if the confidence level is lower, it is important to adapt the activity until the confidence will reach at least 7/10. [20]

Self-management has shown to have various positive effects. For example:

- Positive Changes of behavior: It has resulted in increased use of preventive measures, an increase of minutes trained daily, an increase of use of relaxation methods
- Health status improvement: Pain, fatigue and levels of disability have been reduced
- Fewer care utilization: Patients have had less utilization of the care system [47]

All this can be achieved by taking the right measures to improve patients' self-management skills. Which measure is appropriate at which time must be decided individually. Factors influencing the measures would be: readiness to learn, stage of change and health belief. [20]

1.6.6 Self-efficiency

Self-efficiency is a key outcome necessary to improving patient empowerment. Without self-efficiency, knowledge will not be converted to action and clinical outcomes will not improve as much as they can. In general, self-efficiency describes the probability of someone doing and achieving what he/she set out to do. Therefore, to improve patient empowerment one needs to also improve the patients’ self-efficiency.

The answer improving self-efficiency is not quite clear, although strong suggestions can be made. Programs aimed at improving self-efficiency must consist of four important ingredients: performance mastery, modeling, interpretation of symptoms and social persuasion.

Performance mastery refers to patients taking action. Firstly, they need to grade their ability and their likelihood of achieving their goals. If they are not grading it with 7 or higher on a scale from 0-10 as previously alluded to, they will need to make the goal easier to achieve until a grade of 7 or higher may be noted. Achievable goals strengthen motivation and self-confidence. [20]

Modeling is one important part of improving self-efficiency. It refers to taking part in communities, with similar problems and talking about it. Participants are encouraged to present their problems to the group and the group will try to help them with their current state of knowledge. A leader with medical background and knowledge will try to summarize the problem and opinions offered by the group, as well as offer the correct way of dealing with the problem. Often patients already have sufficient knowledge about dealing with problems, because they have already had that problem or educated themselves about it. Through using this, knowledge can be deepened [21] and self-esteem improved. The person that is offered advice can also profit from this method, as they feel more understood. [20]

Interpretation of symptoms refers to encouraging patients to change their thinking regarding symptoms they currently suffer from. This can happen through conversations with professionals or also in group contexts. One example is patients suffering from fatigue might not think that their fatigue is a result of too little exercise, as it is widely known that normally exercise tires you out. Through discussion with others there can be a change in explanation of the cause for symptoms experienced, this will in turn lead to patients trying new methods to deal with their diseases, for example regularly exercising to improve low energy levels. [20]

Social persuasion is another important factor in establishing change. If a patient wants to make a change, a supporting environment is key. People are more likely to follow the path of change if their social environment is willing to make the same change. If patients want to quit smoking for example it is important for them to surround themselves with people, that also want to stop or do not smoke. If everyone around you is doing what you want to stop doing, you are more likely to fail. [49]

If these four ingredients of a program are included, self-efficiency can be improved and many associated positive health outcomes can result. [20]

1.7 Benefits of Patient empowerment

1.7.1 Improved patient outcomes

Empowered patients have better health outcomes, compared to people who are not. According to a recent Randomized Control Trial (RCT) study by the Charitee University [13] in which patients, a cohort of Cancer Patients Aged $\geq$ 65 Years in the perioperative setting, who were well informed about their disease and how it can be influenced had significantly lower postoperative pain compared to the non-informed cohort. Many studies have shown that adherence to medication prescribed by a health care professional depends on various aspects of patient empowerment. For example, patients, with a high level of self-efficiency tend to have a significantly higher likelihood of adhering to a prescribed medicine. Similarly, HLOC plays a big role when it comes to medication adherence. Patients, who see themselves as being able to influence their own health tend to have better adherence to their medication than people with different control beliefs. [7] The same study also showed that a HLOC on the doctor had better adherence compared to other groups. That is why a shared decision making is thought to be the optimal way of promoting medication adherence. [15]

1.7.2 Increased Patient satisfaction

PE also leads to a higher degree of patient satisfaction. There have been numerous studies that have shown that better education and shared decision making in the process of educating a patient result in overall higher patient satisfaction. [35] [50] A higher degree in patient satisfaction can also promotes other health associated factors that contribute to a better quality of life. [50]

1.7.3 Better relationship to the doctors

Patient empowerment allows for better communication between doctor and patient, this results in a better relationship between the two. If doctors can encourage their patients to actively ask questions and share their perspectives, this can lead to a much better understanding from both sides. This active bi-directional discussion is fundamental to shared decision making (SDM). Furthermore, SDM is known to increase patient satisfaction and confidence in decisions made. [35] Good communication between doctors and patients can also help the doctors understand the health literacy level of a patient and then tailor possible interventions to the patient’s needs. Patients are then more likely to share their anxieties and beliefs with their doctors, which can help avoid misunderstandings and contribute to better medication or treatment-adherence.

1.7.4 Lower health care costs

One cannot mention patient empowerment and not touch on health care costs, as these two are strongly linked. Hibbard and Co-Authors have shown that the per capita health care cost correlate with the level of patient activation. Patients with a very low activation score have a 8-21 percent higher per capita health care cost compared to those with higher activation score. [15] Hammond, Lincoln, and Sutcliffe have shown that Patients who had training for self-efficiency techniques, such as modeling and goal setting, are more likely to take preventive measures like joint protection, as in this study. [51] Empowered patients also tend to have a better symptom perception which leads to a reduction in emergency care attendances shown in the study, “Effectiveness and Cost-effectiveness of an Empowerment-Based Self-care Education Program on Health Outcomes Among Patients with Heart Failure”. The same study has shown that the intervention, which was a 12-week educational course, resulted in better self-management skills, which also contributed to significantly lower health care costs. [11] [50]

1.8 Challenges to Patient Empowerment

1.8.1 Health literacy

Health literacy varies significantly among the population, even though, it is one of the most important indicators of patient empowerment. The US government healthy people 2030 initiative defines personal health literacy as *the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others”.* [52] As mentioned above, there are three levels of health literacy, where each level can only be reached by reaching the lower levels before. These levels are functional health literacy, as the main focus in this definition, interactive health literacy and critical health literacy. These levels are reached in a stepwise manner, where one cannot get to the highest step or level, without first reaching the lower steps/levels.

Health literacy and patient empowerment can be likened to conjoined twins. Patient empowerment and health literacy can only be effective if both are at high levels. Health literacy without high levels of empowerment may create an unnecessary dependence on health care professionals. High levels of empowerment without health literacy may lead to wrong decision making. [53]

Patient information needs to be targeted on patient's heath knowledge at baseline to improve their overall health literacy. There are many positive effects that are associated with high levels of health literacy, such as improvement of health status (self-reported), increase in overall health knowledge, decrease in cost and hospitalization time and less frequent healthcare utilization. [54, 55]

Health literacy is influenced by many factors. Most important factors to influence health literacy are:

- Sociodemographic: socioeconomic background, employment, income, language etc.
- Personal: Age, race, gender
- General literacy
- Abilities: reading, listening, hearing, seeing
- Parental influences
- Media use [56]

Unfortunately, initiatives that especially target groups of low health literacy levels are few in numbers. This leads to an unequal distribution of health literacy levels among the population. But especially the disadvantaged and low health literacy population could profit the most of interventions improving health literacy and empowering strategies. [38, 57] Initiatives that especially target these groups and furthermore higher levels of health literacy in these groups are sorely needed. [57] [56]

1.8.2 Patients readiness to be empowered

Many factors contribute to the patient's willingness to be empowered. Low health literacy and inadequate health related competencies of patients are important factors that may lead to unwillingness to be empowered. In addition, a lack of confidence from the patient's side is also seen as a big barrier for patients' willingness to participate. These factors may especially gain importance in the management of acute disease. The patients then seem to want the provider to focus all their attention to the treatment of the acute illness, rather than on empowering them. [58] As mentioned above, empowering strategies do not aim at forcing patients to decide on their disease alone, it is about facilitating the process of taking part in health-related decisions. With gaining competencies, self-confidence also rises and empowerment is ore appreciated. [20, 49, 58]

1.8.3 Providers readiness to empower patients

One barrier in patient empowerment is the perspective of health care practitioners. Many factors contribute to the willingness to empower patients. One important factor is the point of control. Many health care professionals are unwilling to distribute the point of control among them and their patients. [59] Giving responsibility to their patients and power to manage their own disease, relinquishing control over management. Health care professionals do not think that patients would have the capacity to manage their own disease as well as they do and thus do not want to relinquish this control. [59]

Another important factor is the time needed to implement patient empowering strategies. It is not clear yet, how much time is necessarily required from practitioners to engage in these strategies. Health care practitioners may perceive implementation as time consuming in an environment where time already feels too little and this may hinder them engaging in these strategies. [22]

Other factors that contribute to doctor´s willingness are the type of disease, the doctor´s specialization and personal attitude towards medical decisions. [22]

1.8.4 Adequate information

One important task in patient education is to provide patients with resources that are both readable and reliable. This is easier with educational interventions given by a doctor but the problem of reliability and readability arises in the context of patients seeking for information online. Many studies have shown that website resources of medical information are of poor quality or have a highly variable quality. [60-63] That leads to patients self-diagnosing, and self-treating whilst being highly misinformed. [64]

Medical information obtained online may be wrong due to many reasons. Old information that has not been updated, one sided discussion on treatment options, authors who have hidden agendas of selling certain products, which could sometimes be fake products as well. One website was seen to be offering T-Cells for online purchase. When questioned on accidental overdosing of this product the company replied "Oh, they won't hurt you." [64] When information is not blatantly wrong, it may be incomplete, these all leave the patients misinformed and unable to make an informed decision about their disease and management thereof. [60]

The second problem in the context of educational online information is readability. Overall, many resources show an inadequate readability. For example, in one study, readability and quality of internet resources regarding Raynaud´s phenomenon and early detection of systemic sclerosis was investigated, both quality and readability showed poor results. [60]

In order to provide patients with reliable and readable information, it is important to give them enough information and also to tell them, where to find reliable, up-to-date information, if they felt the urge to advance their knowledge. It is important to keep educational patient resources readable for all levels of health literacy and to tell them how to decipher the reliability of a website. [64]

1.8.5 Limited communicational skills of health care professionals

A common problem in health care is that of the limited amount of time that health care professionals have. Most of the communication regarding decisions about your disease is communicated from doctor to patient, misunderstandings can arise, especially in stressful situations. It is important to acknowledge, that patients are often in stressful situations, when being at the doctor’s office, and only few of the information transferred verbally can be recalled minutes, and even less in days, after they leave the office. Up to 40-80 percent of information transferred to patients in the office is forgotten immediately [24]. Recall six days after a surgical procedure can be very low, even if patients feel like they were given adequate information to make an informed decision. [65] Thus, it is important to try to create a low-stress atmosphere good interaction in conversations with patients. Good recall leads to patient's satisfaction and adherence. [24]

There are some methods in advancing the information transfer between doctor and patient verbally. One important method is the teach back method, that has already been discussed above. [25] Factors that contribute to low recall include clinician related factors like the language used and time spent explaining, information method being spoken vs. written and patient factors like that of literacy and expectations. [24]

In order to empower patients, it is important to take the time to discuss problems, options and fears of the patients. The total amount of time, necessary to communicate on a highly-empowering level is unclear. [22]

A big danger of patient disempowerment arises in the context of insensitivity to patients, with low health literacy levels. Health care organizations´ sensitivity to low health literacy helps to identify those who are at a higher risk of disempowerment and to tailor intervention to their needs. Patient empowerment initiatives have great positive effects on their knowledge when aiming at their active involvement. [58]

1.8.6 Intelligent non-adherence

Patients autonomous activity regarding healthful behavior is thought to be the main reason why patient empowerment strategies have positive effects on health outcomes. Though, this might not be true when it comes to medication adherence. While some patient empowering strategies have beneficial effects on adherence (information search and knowledge) others (decision participation) might have negative effects on medication adherence. [7] The term "intelligent non-adherence" is becoming a well-known term in adherence studies. Intelligent non-adherence means that patients start overruling the physician's choice because of their high levels of health literacy and strong involvement in treatment decisions, out of rational reasons. [7] Common reasons for stopping the treatment are misdiagnosis or side-effects. [66] This would imply, that the decision made by the patient is right, but only if the patient's high levels of autonomy are accompanied by equally high levels of health literacy. [7] In situations where decision making skills and knowledge are not as good to make an informed decision, this non-adherence can have negative effects. [53]

1.9 Text simplification of patient reports

In this paper we will discuss one specific method in Patient Empowerment. As thoroughly discussed above, one key aspect of Patient Empowerment is education. The effectiveness of educational methods depends on many factors. One important factor of educational effectivity is the understandability and reliability of the educational resource.

When patients leave the hospital after an investigation was done, they often shortly talk to a medical professional and then are discharged home with a written summary of their hospital stay or the investigation that was done. This summary is called the patient report. It is meant to summarize the most important outcomes and findings made, so that it can be used in treatment and management and by other medical professionals, who are involved in the treatment of the respective patient.

Unfortunately, this patient report often contains medical terms, that are hardly understandable to medical lay-person. Since patients do not remember everything they are told in the discussion with their medical professionals, they are reliant to this patient report until their next appointment to a medical professional. That is why it is of great importance to translate the medical terms used in the original patient report into a version, that is easy to understand for patients alone, so that they do not have to rely on others to understand their patient report. With that patient centered version of the patient report, patients can take an active role in their disease-management.

1.9.1 Project simplifAI

This paper is part of the project simplifAI. The aim of the project is to use artificial intelligence (AI), with deep learning techniques of natural language processing (NLP) to simplify medical texts, anonymize patient reports efficiently and enable efficient use of EHRs in future.

Patients often find themselves overwhelmed by the medical terminology used in health services. When confronted with these complicated terms, patients lose control over their situation, and cannot participate in their own health anymore. They rely to their primary care physician to have their results explained to them. Of this perceived disempowerment various negative effects result, such as lower levels of understanding, participation and motivation, overall lower perceived empowerment. Anxiety, disempowerment and uncertainty lower the patient´s trust in medical services and pave the way to dissatisfaction and misinformation.

One of the results of this situation is the well-known “Dr. Google phenomenon” [67]. In the time between discharge of poorly informed patients at the hospital and the follow-up appointment with the primary care physician patients try to find information by themselves, which often even worsens their anxiety and perceived control. The development of reliable educational material and readable medical reports in EHRs, that are available at any time to the patient, would make it unnecessary to use resources of unreliable and poor quality.

1.9.2 Goals of simplifAI

The project simplifAI defined three main goals in forming an intelligent system for dealing with patient reports in future. These goals are:

- **Automatic generation of simplified patient-centered medical reports**. The general outcome of this project is the implementation and training of a deep learning language model that summarizes radiological reports as accurately as possible and explains medical terms in a patient-friendly way. We set the processing of 10.000 radiology reports and 1.000 non-radiology medical reports as a benchmark for this goal.
- **Privacy-preservation and medical report de-identification**. Medical data is among the most sensitive data and must therefore be reliably anonymized so that we can process it in compliance with the GDPR (General Data Protection Regulation). Since sensitive information can also be found in the body text of a report, we have to develop novel de-identification tools. Federated learning will allow privacy-sensitive data to remain with the medical provider and still contribute to the learning process of a global language model.

- **Infrastructure and standardization for the transfer of reports between radiology practices and patients**. We will develop necessary infrastructures and interfaces to support existing EHR management systems and to establish a platform environment that allows patients to upload and simplify medical reports

1.9.3 Text simplification of medical texts

Text simplification in the medical domain is not a new idea. Many different projects focused on translating medical text into simplified versions. These projects often used rule-based translation methods, which translated medical terms, lexicon based, into understandable terms for medical layperson. These approaches lacked in effectiveness and usability since its high demand to be reevaluated and updated.

Deep learning techniques in contrast have the ability of learning by themselves, under supervision. Machine learning approaches guide the future of text simplification in medical domains. One of the huge drawbacks into the development of these artificial intelligences is data-protection- and privacy-concerns. Since machine learning approaches need a lot of data to learn from, it is necessary to provide a large data-corpus for them to be established. Sensible medical data has made it difficult to find this important dataset, especially in the German-speaking language.

1.9.4 Research of this paper

In our research we are analyzing the difference in patients understanding and levels of concern after reading radiological patient reports as usual, including many, for medical lay-people difficult-to-understand medical terms, and after reading simplified radiological patient reports.

As previously discussed, patients often do not understand what they are told by a medical professional and much of what they do understand, cannot be remembered after a short verbal discussion. Up to 80 percent of what patients hear from the physician is forgotten immediately. What they are left with is their patient report, a form of written information they can hold on to and read through in a low-stress environment.

Written information can advance patients understanding about their disease a lot and also influence many other outcome-defining measures. Studies have shown that understandable printed summary texts at the end of a hospital stay can improve patients understanding, form a better relationship of patients to their doctors, improve satisfaction and motivate them to adhere to treatment plans. [68]

In the English language the text simplification or translation tool has already been implemented, for example by the University of Utah and it´s open-access, collaborative consumer health vocabulary (CHV) [69] Further research sought to enrich CHV by crawling candidate terms from living corpora such as online health forums and health-related social networks. [70] Recent improvements focus on purely automatic enrichment approaches based on modern machine learning techniques like word embeddings and the usage of semantic networks (WordNet). [71] All these works focus on English explanations of medical terms only.

For the German language, Was hab' ich? [72], a non-profit organization, manually translates medical reports from patients into simple medical language. They also provide an interactive medical lexicon, called Befunddolmetscher, [73] where patients can look up medical terms and the corresponding layperson's explanation. All data is created manually and maintained by medical experts.

This method of simplification is very time consuming to physicians, because they have to manually translate medical questions. In contrast, with deep learning, AI can automatically simplify hardly understandable patient reports, without the need of time from a specific physician. The simplification is aimed at giving patients the ability to understand what was found in the investigations, what was done and what further steps are. This text should enlighten patients about their findings and pave the way to a higher level of participation in future decisions.

Through the AI, the original text is automatically rewritten and the outcome language used is targeted more on average patient’s health literacy levels. It can in future be used on any radiological patient report and transform it into a patient targeted means of written information transfer. Through educating and enlightening patients, they reach a higher level of empowerment.

1.9.5 Hypothesis

After being shown one patient report, that included a lot of medical terms, without explanations, and one patient report with less complicated terms and a lot of explanations, our hypothesis was, that our probands understanding of the second, simplified report will improve, compared to the original one.

The second aim of our research was to analyze the effect of the simplification on the levels of concern of our probands. This led us to the second hypothesis of our research, that the levels of concern, will get more appropriate, after patients read the simplified patient report, compared to their levels of concern after reading the original one. If the results of the fictive investigation showed alarming findings, the level of concern will appropriately rise and rather calming findings will be perceived calming.

To rate the appropriate level of concern for each of the fictive patient reports we asked our friendly colleague, Eva Hassler, to rate the severity of findings of each report, that we used.

2 Methods

2.1 Data collection

We collected the data of our research by means of a survey. Participants were approached between April and November 2022. Eligible participants must have had at least one radiologic examination (X-Ray, CT, MRI, etc.) and be at least 18 years old. The survey was completed 201 times, 15 individuals denied participation, and 5 broke up the survey.

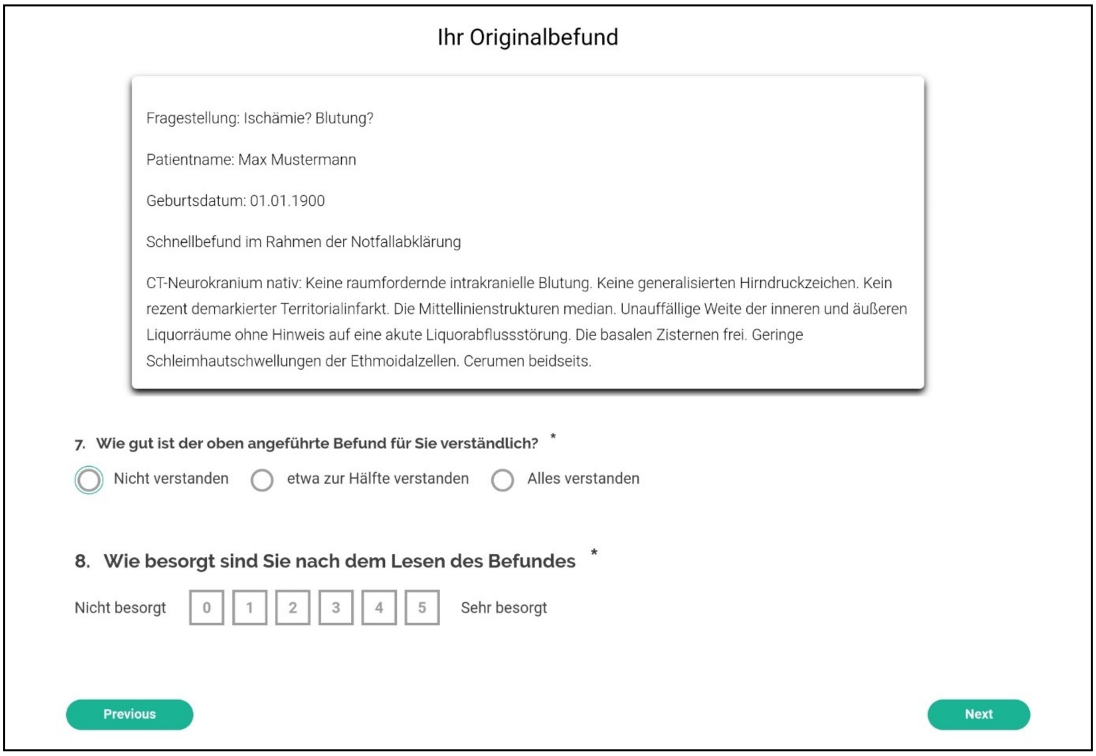
We collected the data at two different areas at the LKH Graz, a tertiary care center in Graz, Austria. Area number one was the MRI Center, at the Radiology building, where there are patients with chronic diseases doing follow-ups. The second area was called the EBA, the initial medical admission center. The participants were mostly ambulant patients, who came with a more acute concern.

Ethical approval for our study was gained by the Ethics Committee of the Medical University of Graz.

The survey, that was used to collect the data, was saved on a tablet and carried from patient to patient. It consisted of five pages, each page had two to six questions. The language of the survey was German, as it is the mother tongue of most people in Austria and the working language used in hospitals. In addition, methods on investigating understanding may be biased by using a different language in the survey due to possibly differing baseline literacy of Austrians in English.

On the first page, patients were asked if they wanted to participate in our research. They were told that the survey is voluntary, anonymous and that they can always quit, without having to give a reason. On the same page the participants were asked about age, gender, how many radiological examinations had already been performed and how often electronic health record platforms, such as ELGA, the most well-known personal health record platform in Austria, were used.

On the second page patients were given a fictive patient report, first in its usual format, containing a lot of medical terms (See: Figure 2), and were asked about how much they understood as well as their level of concern in the findings. They had to decide whether they felt like they understood the information given in terms of: everything (german: “alles verstanden”), about half (German: “etwa zur Hälfte verstanden”), or nothing (German: “Nicht verstanden”). Regarding concern, they had to grade their level of concern from 0=not concerned (German: “nicht besorgt) to 5=extremely concerned (German: ”sehr besorgt”).



Ihr Originalbefund

Fragestellung: Ischämie? Blutung?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Schnellbefund im Rahmen der Notfallabklärung

CT-Neurokranium nativ: Keine raumfordernde intrakranielle Blutung. Keine generalisierten Hirndruckzeichen. Kein rezent demarkierter Territorialinfarkt. Die Mittellinienstrukturen median. Unauffällige Weite der inneren und äußeren Liquorräume ohne Hinweis auf eine akute Liquorabflussstörung. Die basalen Zisternen frei. Geringe Schleimhautschwellungen der Ethmoidalzellen. Cerumen beidseits.

7. Wie gut ist der oben angeführte Befund für Sie verständlich? *

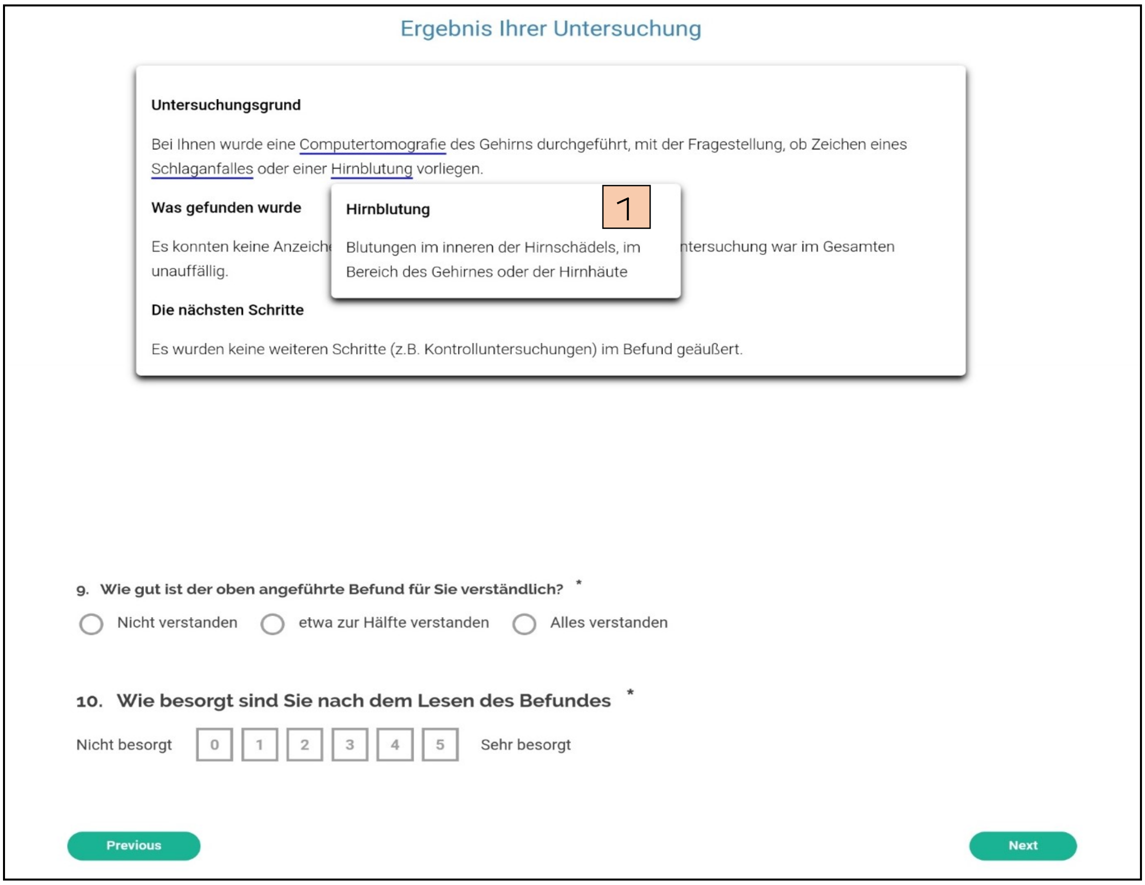
○ Nicht verstanden ○ etwa zur Hälfte verstanden ○ Alles verstanden

8. Wie besorgt sind Sie nach dem Lesen des Befundes *

Nicht besorgt ☐0 ☐1 ☐2 ☐3 ☐4 ☐5 Sehr besorgt

Figure 2: Patient report 1, original version: medical text in German containing a lot of medical terms. Question 7: Understanding (not understandable/about half understandable/fully understandable) Question 8: Level of concern (0=not concerned; 5=very concerned)

After they decided on these answers they were given the simplified text (See: Patient report 1 simplified for example) on page 3. This simplified patient report had the same meaning, but used a different wording and structure. The content was structured uniformly and provided clear headings. The relevance of each heading was clear, and it was leter indicated whether further investigations were planned or what further steps were to be taken. Difficult to understand medical terms were translated into easier, more understandable terms or they were underlined and further explained by clicking on the word and an extra box would pop up with a definition. when the word was clicked on (see Figure 2). The fact that the explanation for some of the terms appears only after one click on the underlined word allowed for people with higher levels of health literacy to continue reading undisturbed and people with lower levels of health literacy to gain equally complete understanding. After reading the second simplified patient report the participants again had to rate their understanding and level of concern. (See: Figure 3). The exact versions of the patient reports, together with the explanations provided, that were used in the survey can be found under 2.2 Patient reports.


Ergebnis Ihrer Untersuchung

Untersuchungsgrund

Bei Ihnen wurde eine Computertomografie des Gehirns durchgeführt, mit der Fragestellung, ob Zeichen eines Schlaganfalles oder einer Hirnblutung vorliegen.

Was gefunden wurde

Es konnten keine Anzeich ntersuchung war im Gesamten unauffällig.

Hirnblutung

Blutungen im inneren der Hirnschädels, im Bereich des Gehirnes oder der Hirnhäute

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

9. Wie gut ist der oben angeführte Befund für Sie verständlich? *

○ Nicht verstanden ○ etwa zur Hälfte verstanden ○ Alles verstanden

10. Wie besorgt sind Sie nach dem Lesen des Befundes *

Nicht besorgt ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 Sehr besorgt

Figure 3: Patient report 1, simplified version: translation of the original patient report 1. Subheadings guide a uniform structure. 1= Box: explanation to the medical term: "Hirnblutung". Question 9: Understanding. Question 10: Level of concern

On the fourth page of the survey patients were asked if they were interested in having their patient report simplified, like they have seen it on the survey. Furthermore, they were asked whether they would be willing to provide anonymized excerpts of findings for further research in the development of AI based text simplification software. The last question was, if they generally were interested in who is using their data.

Together with the levels of concern and understanding, these three questions and the distribution of the answers will be evaluated in the section of results.

After that, on the last page the patients were given a final overview over the two patient reports beside each other. First, the hard-to-understand text and second the simplified one.

2.1.1 Data saving and processing

The data was saved directly on the tablet and gathered there. The data collection was done by means of the survey tool SurveyJS. The data was stored locally on the tablet and transferred to the workgroup server.

The collected data was then transferred from the tablet to another computer. The data was then transferred into an excel file, where all information was being stored and processed. The statistical analysis was done with SPSS.

2.2 Patient Reports

As already discussed, we used five different patient reports, with different fictive scenarios of findings after a radiological examination. The participants were held to imagine, that it were findings for them, so that they could grade their level of concern. The reports differ in length and severity as well as in the terms used to describe conditions. The original and the simplified reports used in our survey can be found in the following.

The main difference of the two patient reports in each survey is, that the simplified reports use terms, that are easier to understand for the layperson and they further offer explanations to certain terms. The simplified patient reports are also more structured compared to the original ones. They consist of three different parts: Reason for investigation, results and further steps to be taken.

In order to guarantee that radiological findings and results used in the study resembled those commonly used in the everyday medical practice, findings were written by radiology professionals of the LKH Graz.

In the following section the reports, that were used in our survey will be shown, in original version, as well as in simplified version. In the simplified patient reports, terms, which might demand further explanations, can be explained while clicking on the word underlined. Because of the format of this paper this function is represented by explanations linked by means of footnotes.

2.2.1 Patient report 1, original

Fragestellung: Ischämie? Blutung?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Schnellbefund im Rahmen der Notfallabklärung

CT-Neurokranium nativ: Keine raumfordernde intrakranielle Blutung. Keine generalisierten Hirndruckzeichen. Kein rezent demarkierter Territorialinfarkt. Die Mittellinienstrukturen median. Unauffällige Weite der inneren und äußeren Liquorräume ohne Hinweis auf eine akute Liquorabflussstörung. Die basalen Zisternen frei. Geringe Schleimhautschwellungen der Ethmoidalzellen. Cerumen beidseits.

2.2.2 Patient report 1, simplified

Untersuchungsgrund

Bei Ihnen wurde eine Computertomografie[1] des Gehirns durchgeführt, mit der Fragestellung, ob Zeichen eines Schlaganfalles[2] oder einer Hirnblutung[3] vorliegen.

Was gefunden wurde

Es konnten keine Anzeichen für diese Erkrankungen gefunden werden. Die Untersuchung war im Gesamten unauffällig.

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

[1] *Eine Methode zur Untersuchung von Strukturen im Körper, bei der diese mit Röntgenstrahlen abgetastet und mit Hilfe eines Computers eine Reihe von Querschnittsbildern entlang einer einzigen Achse erstellt werden.*

[2] *Plötzliche Unterbrechung der Blutzufuhr zu einem Teil des Gehirns aufgrund eines Verschlusses oder Risses einer Hirnarterie.*

[3] *Blutungen im inneren der Hirnschädels, im Bereich des Gehirnes oder der Hirnhäute.*

2.2.3 Patient report 2, original

Fragestellung: PAE, Pneumonie, Pneu?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Kein Nachweis von zentralen oder parazentralen Lungenembolien beidseits.

Kein Pneumothorax.

Kein eindeutiger Pleuraerguss. Kein Perikarderguss. Geringe Aortensklerose. Keine Koronarsklerose.

Vermehrte Lymphknoten, nicht pathologisch vergrößert, mediastinal, hilär und axillär beidseits. In 1. Linie noch diskreter Thymusrest im vorderen Mediastinum.

Kleine Konsolidationen im linken Unterlappen vorwiegend peripher sowie diskrete Milchglasinfiltrate. Fraglich beginnende Infiltrate im rechten Unterlappen sowie im Mittellappen.

Narbige Veränderungen in der Lingula mit auch Bronchiolektasien, Bronchiolektasien auch im Mittellappen. Geringes Mucus Plugging peripher.

Die mituntersuchten Oberbauchorgane, soweit abgebildet und beurteilbar, regelrecht.

2.2.4 Patient report 2, simplified

Untersuchungsgrund

Bei Ihnen wurde eine Computertomografie[1] des Brustkorbs und der Lunge durchgeführt, mit der Fragestellung, ob Zeichen einer Lungenembolie[2], einer Lungenentzündung, oder eines Pneumothorax[3] vorliegen.

Was gefunden wurde

Es konnten Anzeichen für eine Lungenentzündung bei Ihnen gefunden werden. Es zeigten sich vermehrte nicht-vergrößerte Lymphknoten[4]. In Ihrem linken Lungenflügel[5] fanden sich kleine Verdichtungen, sowie unsicher beginnende entzündliche Verdichtungen im rechten Lungenflügel[5]. An bestimmten Stellen zeigten sich Erweiterungen Ihrer Bronchien[6]. An einer Stelle konnte man Narben in Ihrem Lungengewebe sehen. Auch fand man geringe Ansammlungen von Schleim in ihren kleinen Bronchien[6]. Die weitere Untersuchung war unauffällig.

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

[1] *Eine Methode zur Untersuchung von Strukturen im Körper, bei der diese mit Röntgenstrahlen abgetastet und mit Hilfe eines Computers eine Reihe von Querschnittsbildern entlang einer einzigen Achse erstellt werden.*

[2] *Die Behinderung des Blutflusses durch einen Embolus im Lungenkreislauf.*

[3] *Eine Erkrankung, die durch abnorme Luftansammlungen in der Pleurahöhle gekennzeichnet ist und zum Kollaps der Lunge führt.*

[4] *Ein bohnenförmiges Organ, das von einer Bindegewebskapsel umgeben ist. Es ist Teil des lymphatischen Systems und im gesamten Körper zu finden. Es besteht überwiegend aus Lymphozyten und seine Hauptfunktion ist der Immunschutz.*

[5] *Als Lungenflügel bezeichnet man die Lunge einer Körperhälfte.*

[6] *Die großen Atemwege, die von der Luftröhre (Trachea) zur Lunge führen.*

2.2.5 Patient report 3, original

Fragestellung: Appendicitis, Ileus?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Die Appendix vermiformis retrozökal nach kranial ziehend mit kleinen Appendikolithen, insgesamt aufgetrieben bis ca. 8 mm Durchmesser mit perifokaler Fettgewebsimbibierung - vereinbar mit Appendicitis. Kein Hinweis auf freie intraperitoneale Luft, kein Pneumoperitoneum.

Kein Ileusbild. Zum Teil die Darmschlingen insbesondere im Unterbauch kollabiert, eng aneinanderliegend und somit eingeschränkt beurteilbar.

Die parenchymatösen Abdominalorgane ohne rezente Auffälligkeiten. Verdacht auf kleine Nebenmilz ventral bis 8 mm Durchmesser. Keine Cholestasezeichen. Keine Hydronephrose beidseits.

Keine pathologischen Lymphknotenkonglomerate abgrenzbar.

2.2.6 Patient report 3, simplified

Untersuchungsgrund

Bei Ihnen wurde eine Computertomografie[1] des Bauchraumes durchgeführt, mit der Fragestellung, ob eine Blinddarmentzündung[2] oder ein Darmverschluss[3] vorliegen.

Was gefunden wurde

In Ihrer Untersuchung bestätigte sich der Verdacht auf eine Blinddarmentzündung[2]. Ihr Wurmfortsatz[4] zeigt Zeichen einer Entzündung, weiters enthält er kleine Kotsteine. Weiters zeigen sich Entzündungszeichen des umliegenden Fettgewebes. Es besteht bei Ihnen der Verdacht auf eine Nebenmilz[5]. Die weitere Untersuchung war unauffällig.

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

[1] *Eine Methode zur Untersuchung von Strukturen im Körper, bei der diese mit Röntgenstrahlen abgetastet und mit Hilfe eines Computers eine Reihe von Querschnittsbildern entlang einer einzigen Achse erstellt werden.*

[2] *Entzündung des Blinddarms.*

[3] *Eine Störung, bei der es dem Darm (meist dem Dünndarm) nicht mehr möglich ist, den Darminhalt normal weiterzutransportieren (oft aus mechanischer Ursache).*

[4] *Ein kleiner, fingerförmiger Beutel, der aus dem Zökum (dem ersten Teil des Dickdarms nahe dem Ende des Dünndarms) herausragt.*

[5] *Eine Nebenmilz ist eine anatomische Varietät, die durch eine Versprengung von Zellen während der Organogenese der Milz in der Embryonalzeit entsteht.*

2.2.7 Patient report 4, original

Fragestellung: Infarkt?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Rezenter Infarkt cerebellär links im PICA-Stromgebiet.

Punkt- bis kleinfleckförmige Marklagerläsionen in beiden Großhirnhemisphären in erster Linie vasculärer Genese. Altersentsprechende Weite der Liquorräume.

2.2.8 Patient report 4, simplified

Untersuchungsgrund

Bei Ihnen wurde eine Magnetresonanztomografie[1] des Gehirns durchgeführt, mit der Fragestellung, ob ein Schlaganfall[2] vorliegt.

Was gefunden wurde

In Ihrer Untersuchung bestätigte sich der Verdacht auf einen Schlaganfall[2] in der linken Kleinhirnhälfte. Außerdem fanden sich Veränderungen in Ihrer weißen Hirnsubstanz[3].

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

[1] *Bildgebung, bei der anstelle von Röntgenstrahlen Hochfrequenzwellen und ein starkes Magnetfeld eingesetzt werden, um erstaunlich klare und detaillierte Bilder von inneren Organen und Geweben zu erhalten. Diese Technik ist für die Diagnose zahlreicher pathologischer Zustände wie Krebs, Herz- und Gefäßerkrankungen, Schlaganfall sowie Gelenk- und Muskel-Skelett-Erkrankungen von großem Nutzen.*

[2] *Plötzliche Unterbrechung der Blutzufuhr zu einem Teil des Gehirns aufgrund eines Verschlusses oder Risses einer Hirnarterie.*

[3] *Meist degenerative Veränderungen der weißen Hirnsubstanz im Bereich der inneren Grosshirns. Besonders PatientInnen mit Bluthochdruck, Gefäßerkrankungen, Raucher oder Diabetiker können davon betroffen sein. Diese Veränderungen können aber auch unspezifisch sein.*

2.2.9 Patient report 5, original

Fragestellung: Spinalkanalstenose? Spondylodiszitis?

Patientname: Max Mustermann

Geburtsdatum: 01.01.1900

Aktivierte Intervertebralarthrose L4/5 und L5/S bds.

Absolute Spinalkanalstenose L4/L5 im Rahmen einer Ventrolisthese, Hypertrophie der Ligamenta flava und Spondylarthrosen.

Nebenbefund: Miterfasste große Nierenzysten beidseits.

MR-tomographisch keine Hinweise auf Spondylodiszitis, kein Abszess.

2.2.10 Patient report 5, simplified

Untersuchungsgrund

Bei Ihnen wurde eine Magnetresonanztomografie[1] der Wirbelsäule durchgeführt, mit der Fragestellung, ob eine Verengung im Spinalkanal[2] oder eine Infektion/Entzündung einer Bandscheibe mit den angrenzenden Wirbelkörpern vorliegen.

Was gefunden wurde

In Ihrer Untersuchung bestätigte sich der Verdacht auf eine Verengung im Spinalkanal, aufgrund einer Verschiebung[3] eines Lendenwirbels[4] nach vorne. Außerdem fand man eine Verdickung Gelben Bandes[5] sowie Verschleißerscheinungen Ihres Gelenkknorpels.

Zusätzlich zeigten sich beidseitige Nierenzysten[6].

Die weitere Untersuchung war unauffällig.

Die nächsten Schritte

Es wurden keine weiteren Schritte (z.B. Kontrolluntersuchungen) im Befund geäußert.

[1] *Bildgebung, bei der anstelle von Röntgenstrahlen Hochfrequenzwellen und ein starkes Magnetfeld eingesetzt werden, um erstaunlich klare und detaillierte Bilder von inneren Organen und Geweben zu erhalten. Diese Technik ist für die Diagnose zahlreicher pathologischer Zustände wie Krebs, Herz- und Gefäßerkrankungen, Schlaganfall sowie Gelenk- und Muskel-Skelett-Erkrankungen von großem Nutzen.*

[2] *Der Spinalkanal ist der Wirbelkanal. Das ist ein Kanal in der Wirbelsäule. In ihm liegt das Rückenmark.*

[3] *Veränderung der Position eines Organs oder eines Teils eines Organs gegenüber seiner anatomisch korrekten Position.*

[4] *Einer der fünf Knochen, die sich zwischen den Brustwirbeln und dem Kreuzbein im unteren Teil der Wirbelsäule befinden.*

[5] *Bänder der Wirbelsäule, die jeweils zwischen den Wirbelbögen zweier benachbarter Wirbel ausgespannt sind.*

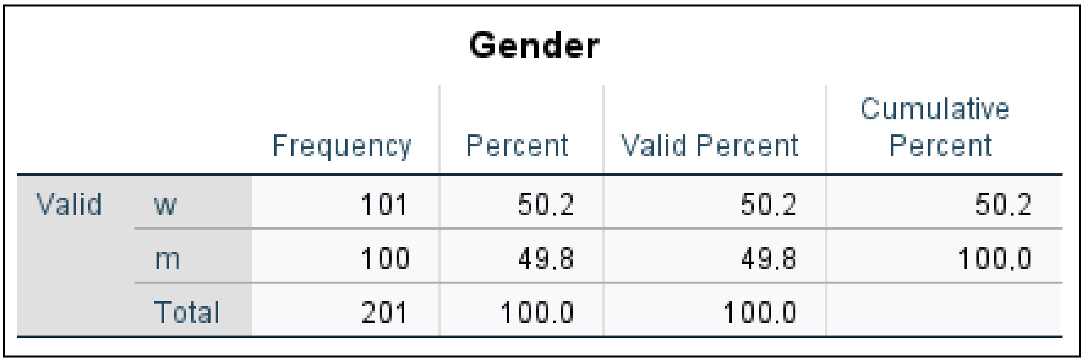
[6] *Abnormaler, mit Flüssigkeit gefüllter Sack innerhalb der Niere, entweder erworben oder angeboren.*

3 Results

A total number of 201 participants completed the survey. Five patients broke up the survey because they did not want to participate anymore or they had to go somewhere else immediately. Only the completed surveys were analyzed in the evaluation. 131 patients completed the survey at the EBA, the primary admission center, and 70 patients completed it at the MRI center.

We investigated differences in understanding and levels of concern after reading the first and the second fictional patient report.

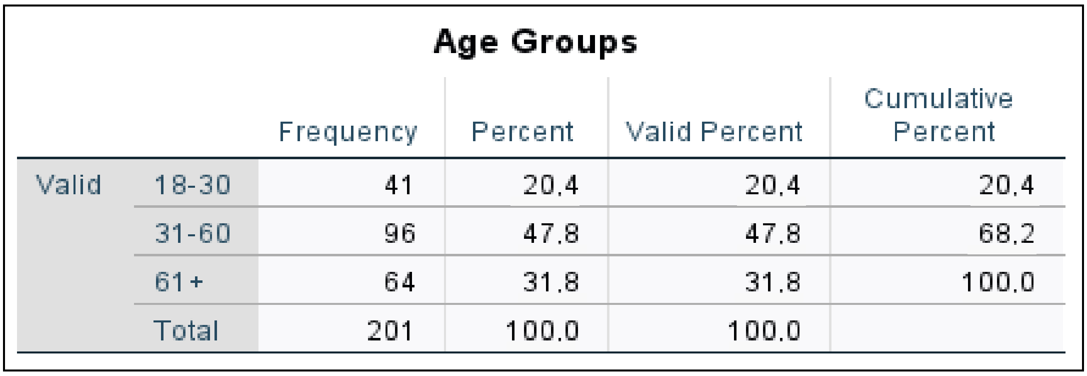
Gender and age distribution. Concerning distribution in terms of gender and age, of our 201 participants 101 were female and 100 males, so there was no significant difference in gender groups. We separated the participants in three different age groups. Age group 1 was defined by ages 18-30, age group 2 by ages 31-60 and age group 3 contained participants with ages 61 or above. Of our 201 participants 41 (20.4%) were categorized in group 1, 96 (47.8%) in group 2 and 64 (31.8%) in group 3.



Gender

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	w	101	50.2	50.2	50.2
	m	100	49.8	49.8	100.0
	Total	201	100.0	100.0	

Figure 4: Distribution of Gender in our survey (w=female participants, m= male participants).



Age Groups

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	18-30	41	20.4	20.4	20.4
	31-60	96	47.8	47.8	68.2
	61+	64	31.8	31.8	100.0
	Total	201	100.0	100.0	

Figure 5: Distribution of Age groups in our survey. Age group 1: 18-30; Age group 2: 31-60; Age group 3: 61+

3.1 Patient understanding

We evaluated the levels of understanding, by asking patients to grade their comprehension, subjectively on a scale from 0 to 2, where 0 means that they did not understand the patient report, 1 that they understood little of it and 2, that they understood almost everything or everything.

After reading the first and second patient report, they were asked the same question in the abovementioned format (See: Figure 4 and 5).

After reading the patient report in its original structure, 47.8% of the participants (n=96) said, that they did not understand (not understandable, 0) the written information given. 45.3 % (n=91) said, that they understood about half of it (little understandable, 1) and only 7.0 % (n=14) said, that they understood everything (fully understandable, 2) of their medical report.

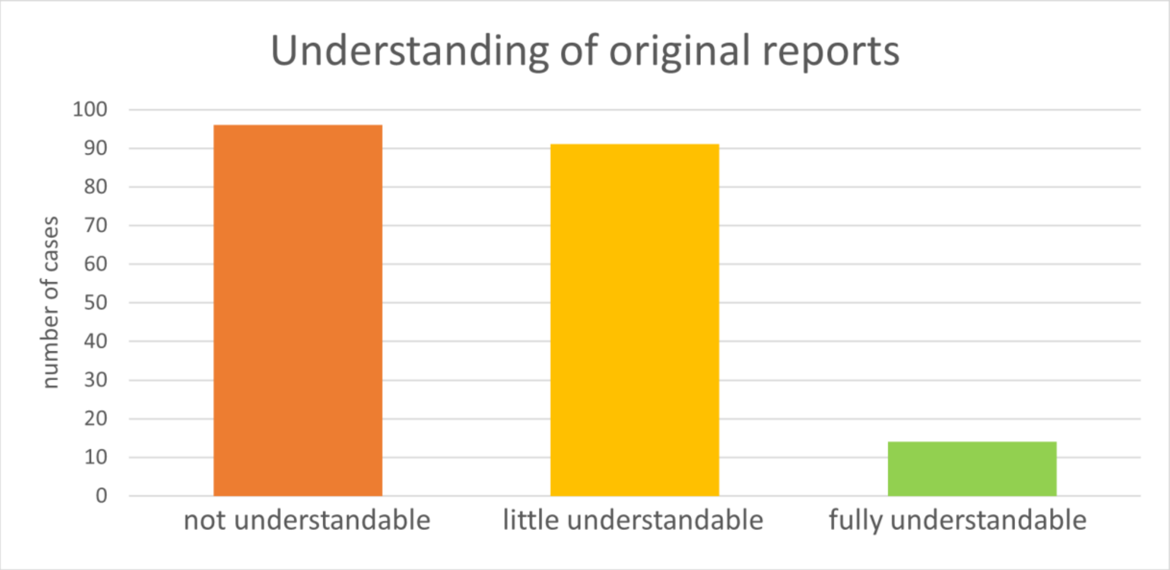


Figure 6: Understanding of original patient reports: Poor understanding of the original patient reports.

In contrast to what was found in terms of comprehension of the original patient report we evaluated the levels of understanding after reading the second, simplified patient reports, and found significantly higher levels of understanding. After reading the simplified patient report, only 1.5% (n=3) of the participants said, that they still did not understand the information given to them. 19.4% (n=39) said, that they understood some of the information and 79.1% (n=159) completely understood the second report, subjectively.

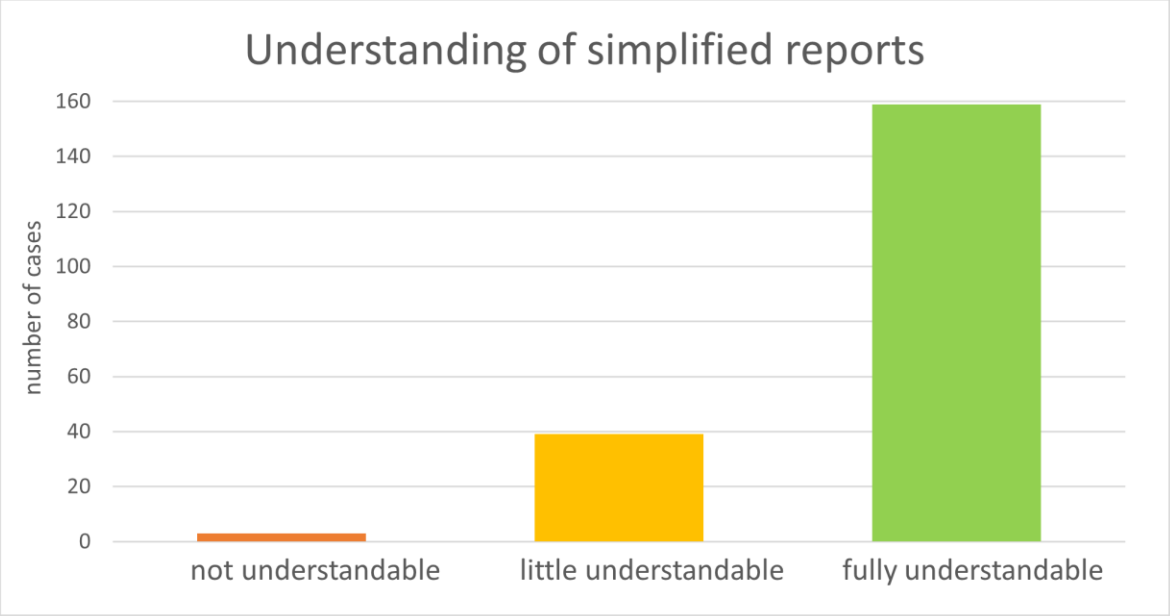


Figure 7: Understanding of simplified reports: Good understanding of the simplified patient reports.

Gender group differences. We tried to analyze if there were differences in understanding between male and female participants after reading the original and then the simplified patient report.

Original patient report: Of the 96 participants who did not understand the original patient report 49 were female and 47 males. In their cohort 48.5% of female did not understand the first patient report and 47.0% of the male participants did not.

46 female participants (45.5% in their cohort) understood about half of the first report, 45 male participants (45.0%) understood about half of it.

6 female participants (5.9%) and 8 male participants (8%) understood everything of the first patient report.

Simplified patient report: Of the 3 participants who did not understand the original patient report 1 was female and 2 were male. Of the female cohort 1.0% of female did not understand the first report and 2.0% of the male participants did not.

20 female participants (19.8 % in their cohort) understood about half of the first report, 19 male participants (19.0 %) understood about half of it.

80 female participants (79.8%) and 79 male participants (79%) understood everything of the first patient report.

We found no significant differences in understanding scores before and after reading the simplified patient reports between males and females. The average understanding scores as well as the distribution of answers did not vary significantly.

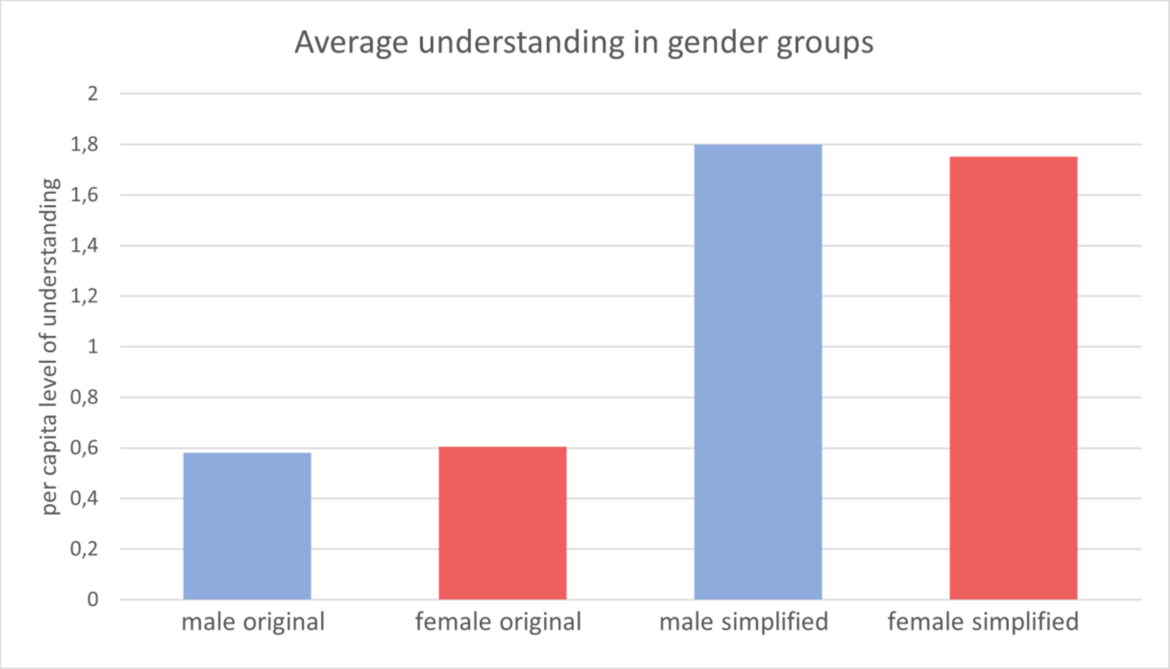


Figure 8: Average understanding in gender groups: Understanding per capita of the original and the simplified patient reports. Not understandable= 0; about half understandable= 1 and fully understandable =2. No difference in average understanding among gender groups before and after simplification

Age group differences. We also analyzed, if there were differences regarding levels of understanding between the age groups after reading the original and after reading the simplified patient reports.

Original patient report: *Age group 1:* 21 (51.2%) did not understand the original patient report, 19 (46.3%) understood about half of it and 1 (2.4%) understood everything. *Age group 2*: 42 (43.8%) did not understand the original patient report, 47 (49.0%) understood about half of it and 7 (7.3%) understood everything. *Age group 3:* 33 (51.6%) did not understand the original patient report, 25 (39.9%) understood about half of it and 6 (9.4%) understood everything.

Simplified patient report: *Age group 1*: 1 participant (2.4%) did not understand the original patient report, 7 (17.1%) understood about half of it and 33 (80.5%) understood everything. *Age group 2*: 1 participant (1%) did not understand the original patient report, 13 (13.5%) understood about half of it and 82 (85.4%) understood everything. *Age group 3*: 1 (1.6%) did not understand the original patient report, 19 (29.7%) understood about half of it and 44 (68.8%) understood everything.

We found no significant statistical difference (Fisher-exact test) regarding the distribution of understanding levels among the different age groups. The distribution did not vary after reading the original patient report and did not vary significantly after reading the simplified patient report. We also compared average levels of understanding per capita in the three age groups. Illustrated in Figure 9 average levels of understanding did not vary significantly among the different age groups.

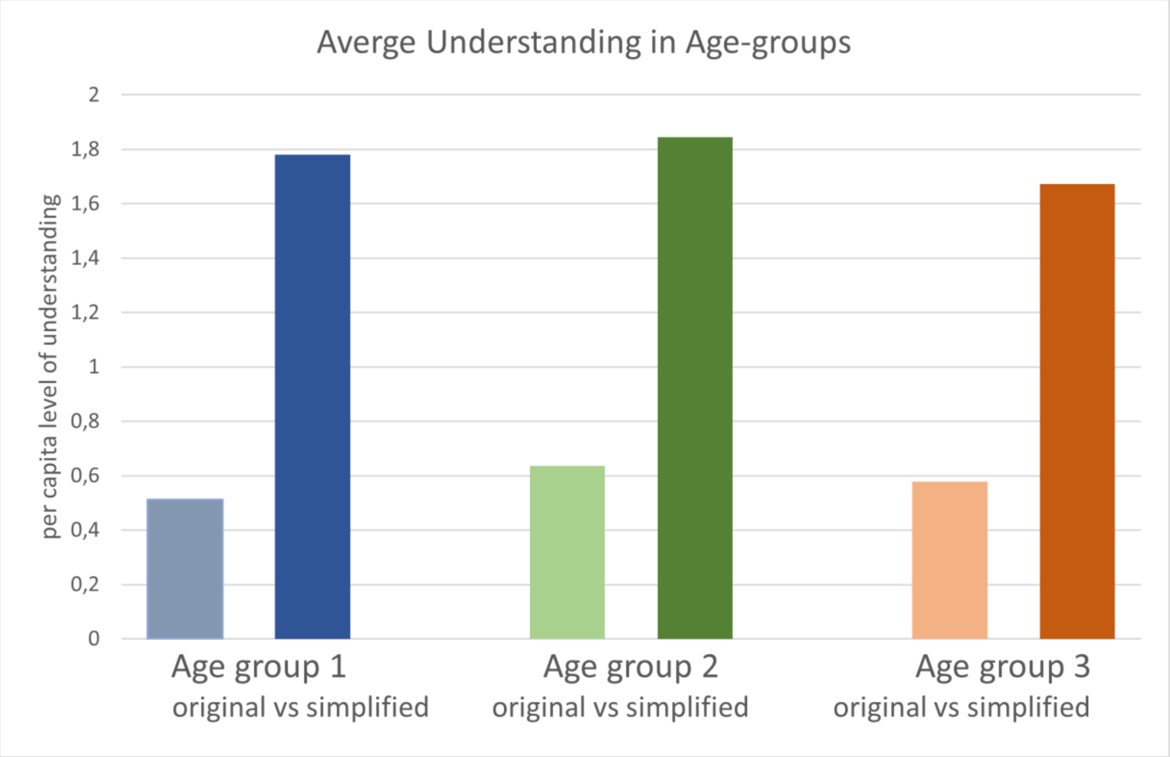


Figure 9: Average understanding in Age groups. Understanding per capita of the original and the simplified patient reports. Not understandable= 0; about half understandable= 1 and fully understandable =2). No differences in understanding regarding Age groups.

3.1.1 Statistical testing of understanding improvement

Using the Wilcoxon-test, statistically highly significant changes in levels of understanding were shown after patients read the simplified report compared to the original report (p=0.000)

Testing of subsets: We found a highly-significant difference in acceptable understanding among all groups (fully understandable and about half understandable) after reading the original patient report and after reading the simplified one using the McNemar-Test. The difference was significant with a niveau of significance of 0.000.

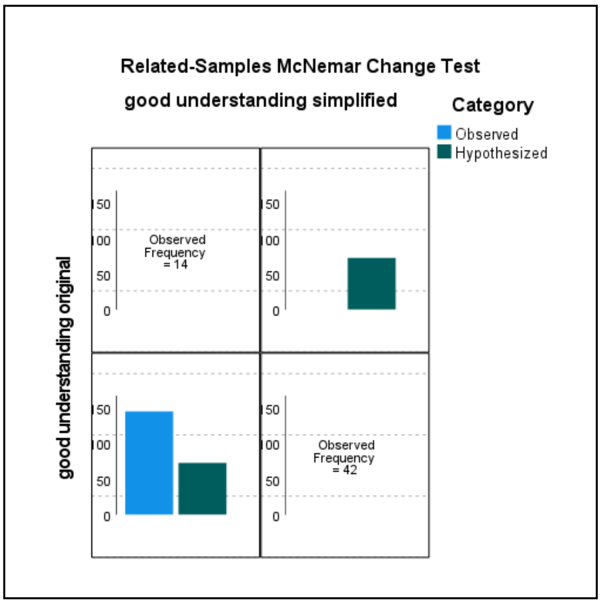


Figure 10: Hypothesized and observed numbers of participants, that fully understood at least half of the simplified patient report using the McNemar-Test.

We also found a highly significant change in perfect understanding (fully understandable) after reading the original patient report and after reading the simplified one using the McNemar-Test. The difference was significant with a niveau of significance of 0.000.

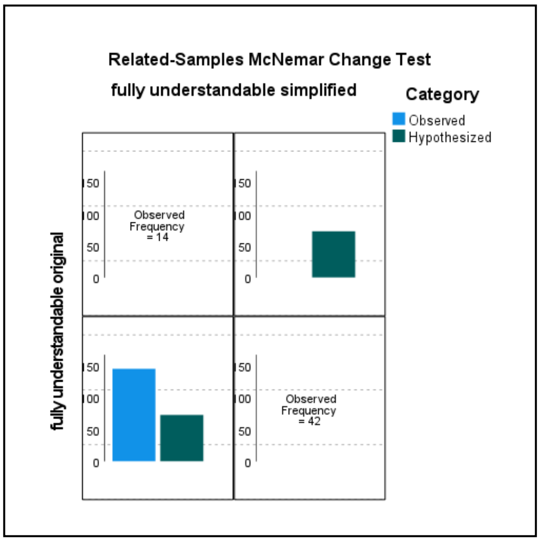


Figure 11: Hypothesized and observed numbers of participants, that fully understood the simplified patient report using the McNemar-Test.

In order to measure individual improvement of understanding levels we also evaluated the change of understanding after reading the first and the second patient report. None of the asked patients had a decrease in understanding after reading the second patient report. 17.9% of the participants had equal understanding of the two reports. 45.8% had a rise of understanding of one grade. 36,3% experienced a rise in understanding of two grades, from the lowest level of understanding to the highest level.

There were also no significant changes in understanding improvement among gender groups and among age groups using the Pearsson Chi-square test.

Differences in Gender Groups: Of 101 female participants 17 (16.8%) did not experience a change in understanding, 46 (45.5%) experienced an improvement of one grade and 38 (37.6%) experienced an improvement of two grades. No one experienced a decrease in understanding grades.

In the male cohort, of 100 participants 19 (19.0%) did not experience a change in understanding, 46 (46.0%) experienced an improvement of one grade and 35 (35.0%) experienced an improvement of two grades. No one experienced a decrease in understanding level.

Differences in Age groups: Age group 1: of 41 participants belonging to Age group 1, 4 (9.8%) did not experience a change in understanding. 22 (53.7%) of the participants experienced an improvement of one grade in level of understanding. 15 (36.6%) experienced an improvement of two grades. No one experienced a decrease in understanding level.

Age group 2: of 96 participants belonging to Age group 2, 17 (17.7%) did not experience a change in understanding. 42 (43.8%) of the participants experienced an improvement of one grade in level of understanding. 37 (38.5%) experienced an improvement of two grades. No one experienced a decrease in understanding level.

Age group 3: of 64 participants belonging to Age group 3, 15 (23.4%) did not experience a change in understanding. 28 (43.8%) of the participants experienced an improvement of one grade in level of understanding. 21 (32.8%) experienced an improvement of two grades. No one experienced a decrease in understanding level.

3.1.2 Differences regarding patient reports in understanding

We also analyzed the outcomes of understanding levels regarding the patient reports. The original patient reports used in our research varied regarding difficulty. As well did the simplified patient reports. We graded the difficulty of terms used in each of the patient reports.

The rating found, that of the original patient reports, patient report 1 was the easiest to understand, followed by patient report 4, patient report 3, patient 5 and patient report 2. Patient report 2 was the most difficult to understand. As we see above, patient report 2 and 5 were longer and contained more difficult terms than patient report 1 for example.

The simplified patient reports also varied in difficulty. The rating was similar to the original patient reports. Report 1 was the easiest, followed by 4, 3, 5, and 2. In our rating, the differences in difficulty were based on the number of difficult translations and the complexity of the findings.

Statistical testing: We found no statistically significant changes in understanding levels of the original report among the different reports.

We found statistically significant changes in levels of understanding of the simplified patient reports among the different reports. Report 1 showed the best understanding of the simplified version, followed by report 3 and report 4. Report 2 and 5 showed worse understanding.

Still, for each of the reports, analyzed separately, a statistically significant improvement could be achieved. Even when only analyzing report 5, the report with the worst understanding after the simplification, a significant improvement in levels of understanding could be shown, using the Wilcoxon-test. (p=<0.001)

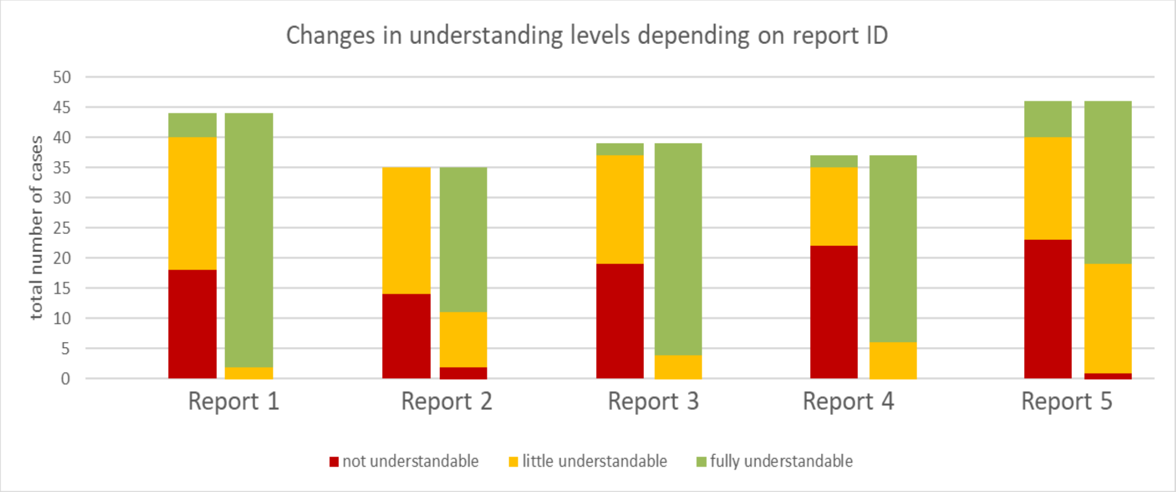


Figure 12: Changes in understanding levels depending on report ID. Report 1-5 show different distributions of understanding before and after simplification. Before simplification: left; after simplification: right. Seperated for each report ID. Red: not understandable, yellow: about half understandbale, green: good understandable.

3.2 Levels of concern

We evaluated the levels of concern, as with the patient understanding, after reading the original patient report and after reading the simplified text. The patients were asked to grade their level of concern acting as if it were their own report. The scale in levels of concern had grades 0 to 5. 0 being that the participant is not concerned at all and 5 being that the participant had the highest possible level of concern (0= not concerned, 1= low level of concern, 2= intermediate-low level of concern, 3= intermediate-high level of concern, 4= high level of concern, 5= very high level of concern).

We evaluated both the overall change in levels of concern and as well as the appropriateness of concern levels. Since we used five different reports each of them was analyzed separately, because appropriate levels of concern varied strongly among the different reports. The grading of appropriate levels of concern was made by previously mentioned colleague, Eva Hassler.

3.2.1 Overall level of concern

We analyzed the levels of concern across all different patient reports after reding the original report and after reading the simplified one. We found, that the median level of concern after reading the original reports was 3 (intermediate high) after reading the simplified patient report it was 2 (intermediate low). Quartile 1 after the first patient report was 2 (intermediate low) and after reading the simplified version at 0 (not concerned). Quartile 4 was at 4 (high level of concern) for both, first and simplified patient reports.

As we assumed, the median level of concern across all patient reports and also the first Quartile was lower after reading the simplified patient report. With the Wilcoxon test we analyzed if the difference was statistically significant. We found, that overall levels of concern showed a statistically highly-significant decrease after reading the simplified patient reports with a p <0.001.

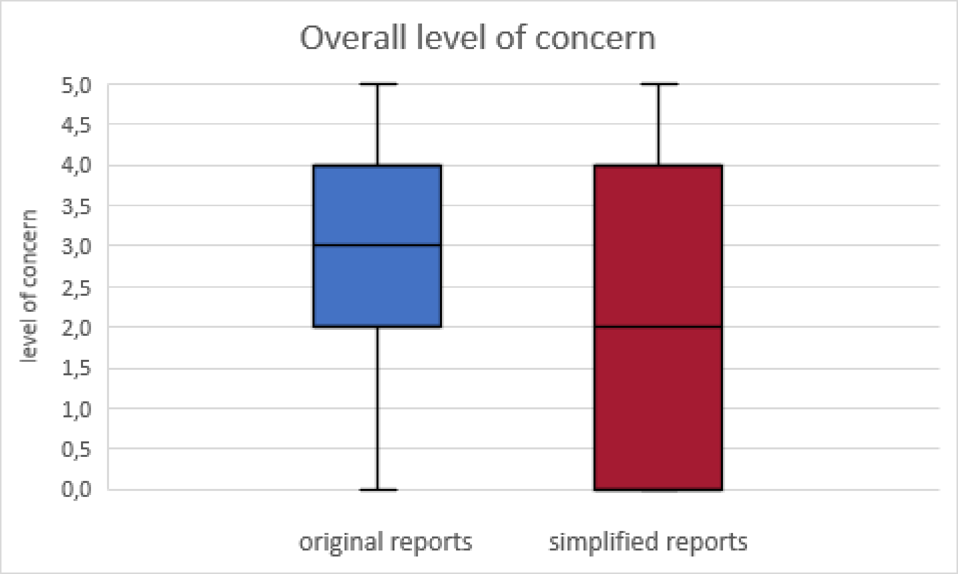


Figure 13: Overall level of concern. Across all Report IDs.

3.2.2 Change in levels of concern

We also analyzed how many participants showed a decrease in levels of concern and how many showed a rise. We found that 54.2 % of the patients showed a decrease of at least one grade of level of concern. 37.8 % showed a decrease of at least two grades at level of concern. In 28.9% of participants the level of concern did not change. In 16,9% the level of concern rose for at least one grade.

3.2.3 Levels of concern in different Report IDs

We also analyzed if the different report IDs had an influence on how significant the decrease in level of concern is. Some of the patient reports included findings that are rather concerning and some did not show severe pathologies. We made the conclusion that changes of level of concern vary depending on the report that was simplified.

We found, that not for all reports statistically significant changes in levels of concern result. For the reports 1, 2 and 3 there have been significant changes in levels of concern after reading the original and the simplified report. Levels of concern decreased for each of these reports. We did not find significant changes in levels of concern for the reports 4 and 5.

In Figure 14 we see, that the decrease in levels of understanding is varying among the different patient reports. Each report will be focused on separately in the following.

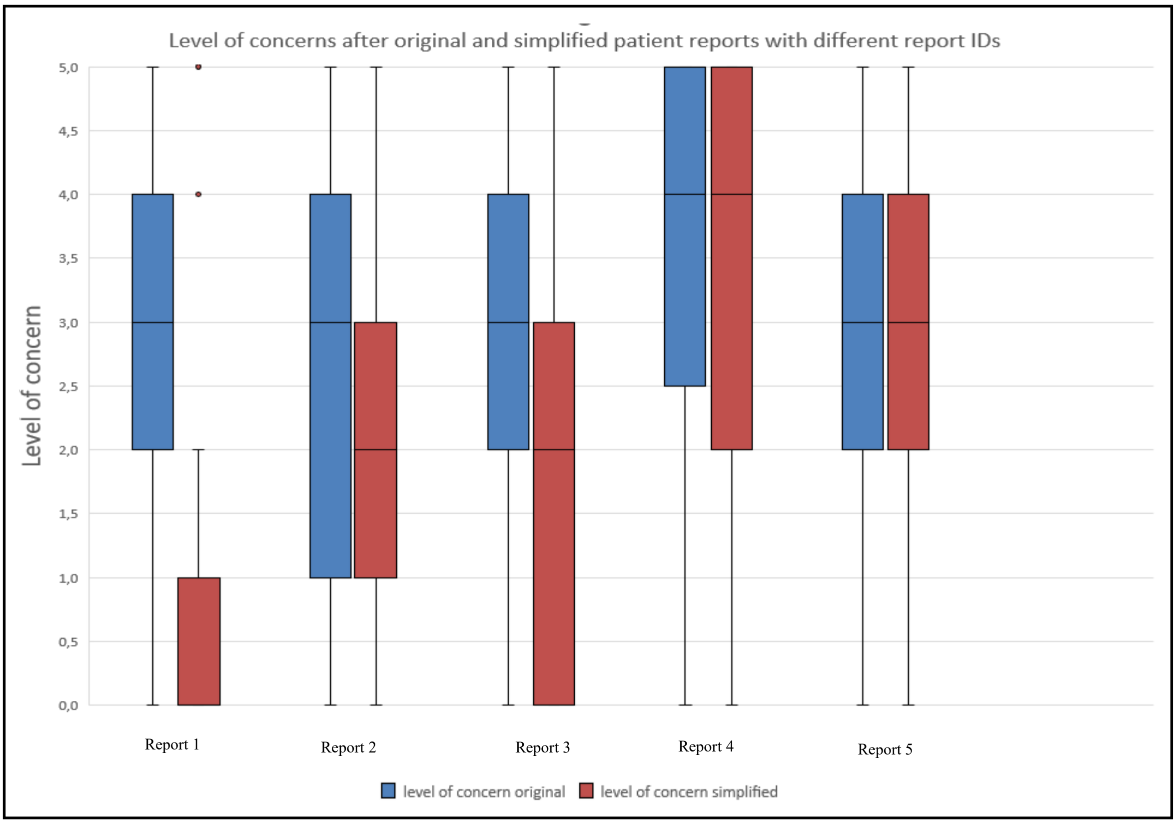


Figure 14: Levels if concerns after original and simplified patient reports with different report IDs: Patient report 1-5 from the left to the right. For each report ID median levels of concern, 1st and 3rd Quartile, after reading the original and after reading the simplified patient report.

3.2.3.1 Patient report 1

The appropriate level of concern for this patient report is low. 0-1 would be appropriate levels of concern.

After reading the first patient report, the median level of concern was at 3 (intermediate high). Quartile 1 was at 2 (intermediate low) and Quartile 3 was at 4 (high level of concern).

Unsurprisingly, after reading the simplified patient report, the level of concern decreased. The median level of concern was at 0 (not concerned) Quartile 3 was at 1 (low concern).

The Wilcoxon-Test showed a statistically highly-significant decrease in levels of concern (p<0.001) after reading the simplified patient report.

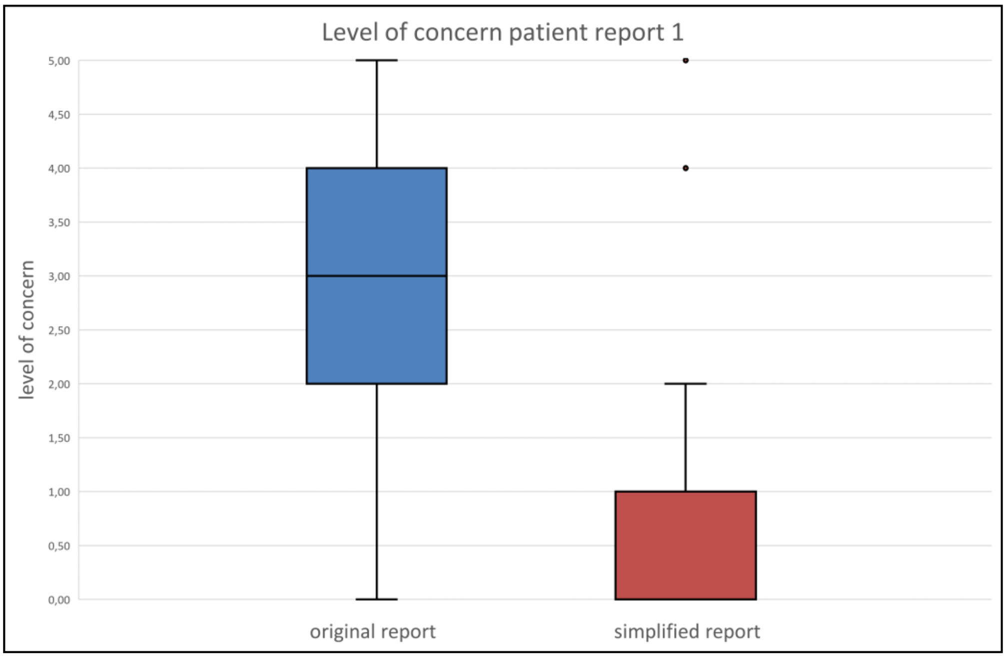


Figure 15: Level of concern patient report 1: blue: Boxplot for level of concern after reading patient report original 1, red: Boxplot for level of concern after reading patient report simplified 1.

3.2.3.2 Patient report 2

The appropriate level of concern for this patient report is intermediate. 2-3 would be most appropriate levels of concern.

After reading the original patient report, the median level of concern was at 3 (intermediate high). Quartile 1 was at 1 (low) and Quartile 3 was at 4 (high level of concern).

After reading the second patient report the median level of concern was at 2 (not concerned) Quartile 1 was at 1 (low) and Quartile 3 was at 3 (intermediate high).

The Wilcoxon-Test showed a statistically significant decrease in levels of concern (p= 0.002) after reading the simplified patient report.

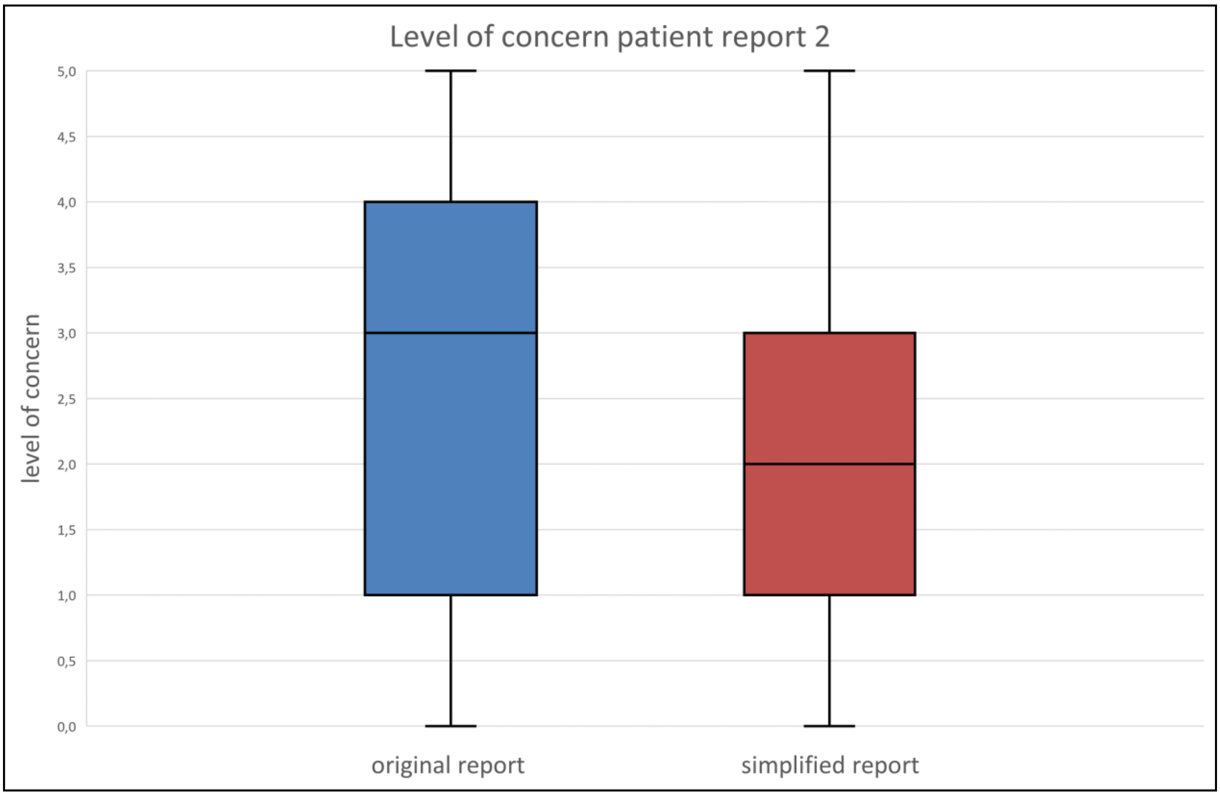


Figure 16: Level of concern patient report 2: blue: Boxplot for level of concern after reading patient report original 2, red: Boxplot for level of concern after reading patient report simplified 2.

3.2.3.3 Patient report 3

The appropriate level of concern for this patient report is intermediate high 3-4 would be most appropriate levels of concern.

After reading the original patient report, the median level of concern was at 3 (intermediate high). Quartile 1 was between 2 and 3 (intermediate) and Quartile 3 was at 4 (high level of concern).

After reading the second patient report the median level of concern was at 2 (not concerned) Quartile 1 was at 0 (not concerned) and Quartile 3 was at 3 (intermediate high).

The Wilcoxon-Test showed a statistically significant decrease in levels of concern (p=0.003) after reading the simplified patient report.

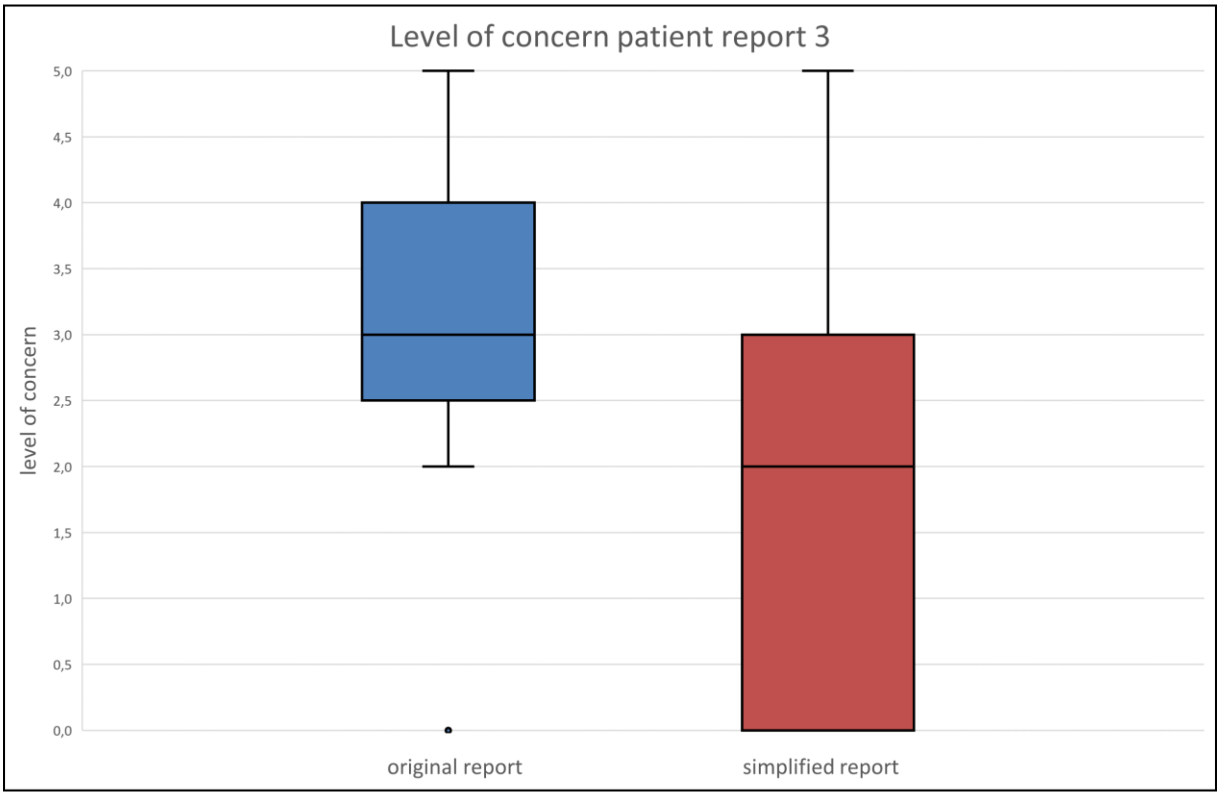


Figure 17: Level of concern patient report 3: blue: Boxplot for level of concern after reading patient report original 3, red: Boxplot for level of concern after reading patient report simplified 3.

3.2.3.4 Patient report 4

The appropriate level of concern for this patient report was high. 4-5 would be most appropriate levels of concern.

After reading the original patient report, the median level of concern was at 4 (high). Quartile 1 was at 3 (intermediate high) and Quartile 3 was at 5 (very high level of concern).

After reading the second patient report the median level of concern was at 4 (high) Quartile 1 was at 2 (intermediate low) and Quartile 3 was at 5 (very high level of concern).

The Wilcoxon-Test did not show a statistically significant change in levels of concern (p=0.761) after reading the simplified patient report.

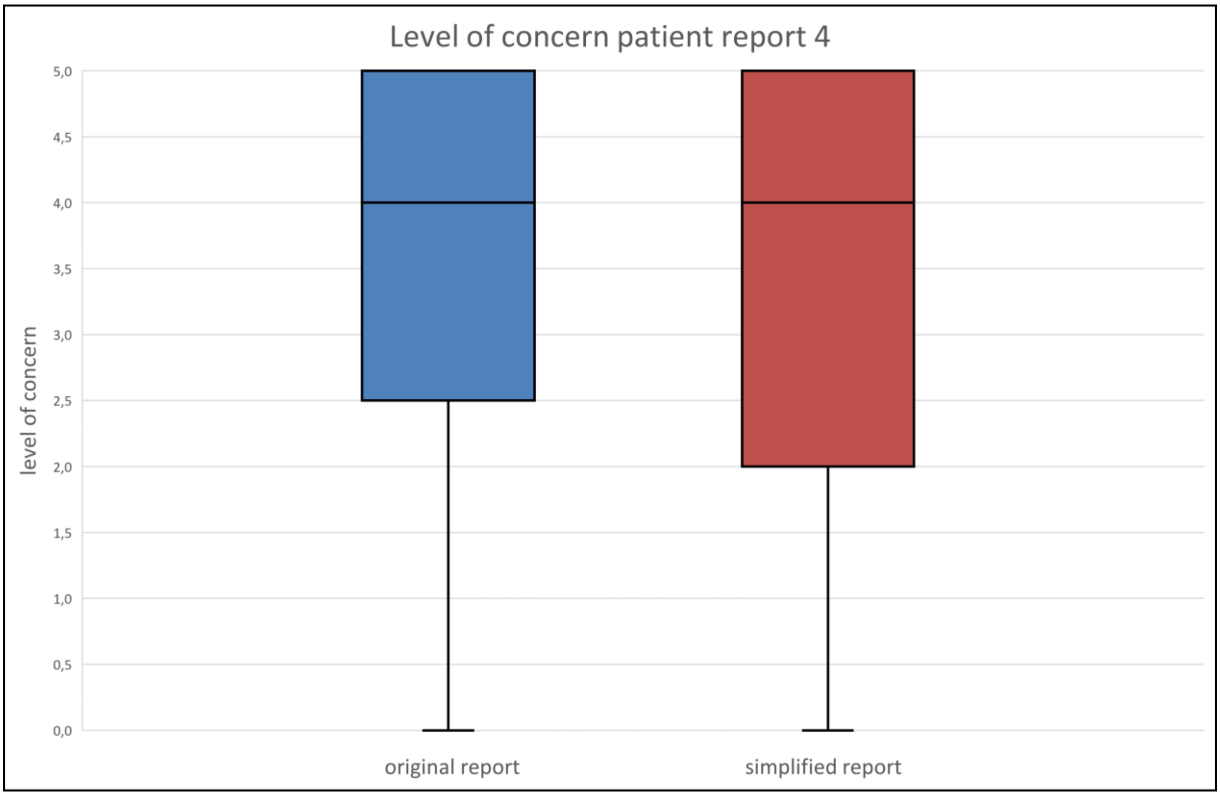


Figure 18: Level of concern patient report 4: blue: Boxplot for level of concern after reading patient report original 4, red: Boxplot for level of concern after reading patient report simplified 4.

3.2.3.5 Patient report 5

The appropriate level of concern for this patient report is intermediate low. 1-3 would be most appropriate levels of concern.

After reading the original patient report, the median level of concern was at 3 (intermediate high). Quartile 1 was at 2 (intermediate low) and Quartile 3 was at 4 (high level of concern).

After reading the second patient report, the median level of concern was at 3 (intermediate high). Quartile 1 was at 2 (intermediate low) and Quartile 3 was at 4 (high level of concern).

The Wilcoxon-Test did not statistically significant change in levels of concern (p=0.174) after reading the simplified patient report.

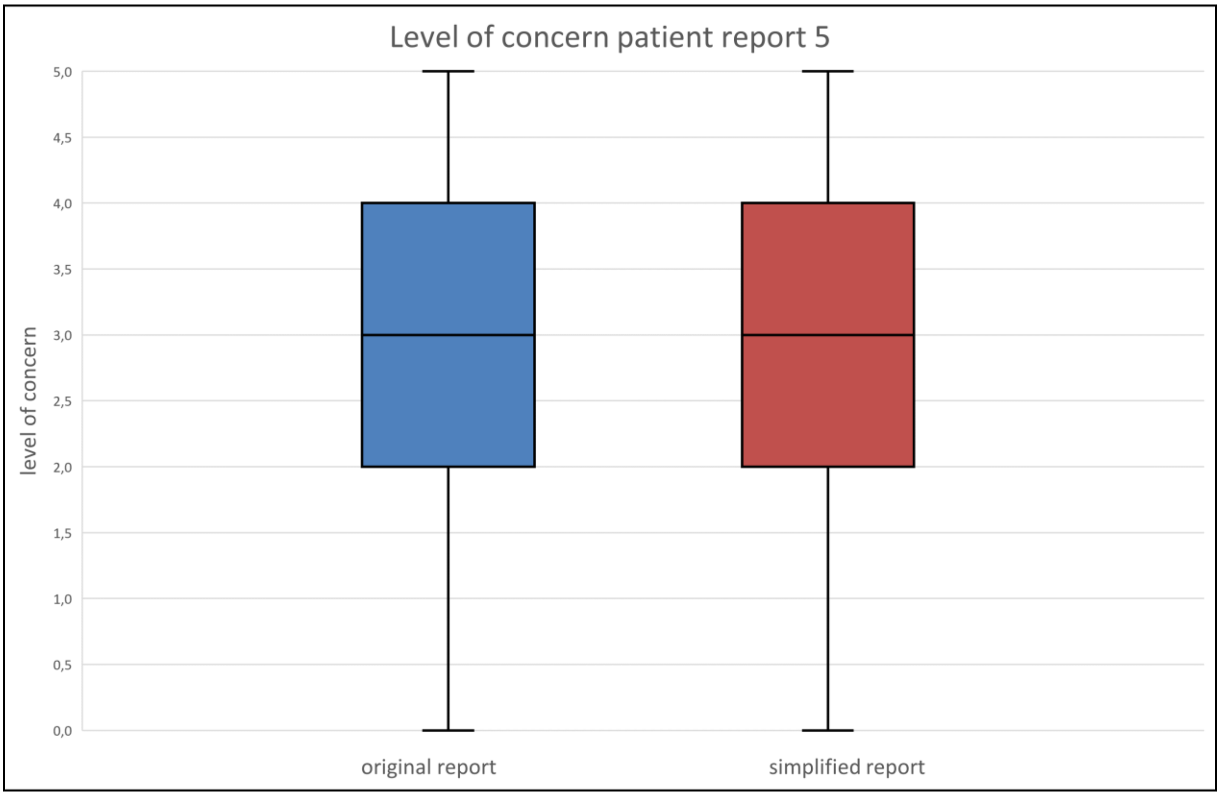


Figure 19: Level of concern patient report 5: blue: Boxplot for level of concern after reading patient report original 5, red: Boxplot for level of concern after reading patient report simplified 5.

3.3 Interest in simplified patient reports

We also asked the participants if they were interested in getting their patient report simplified for free in future, in the same format they have read the simplified patient reports. In our research setting, 90.5% of the participants answered with “yes”. (original: Sind Sie an einer kostenlosen Befundvereinfachung interessiert?). 9.5% said, that they were not interested.

Differences in gender. There were no significant differences regarding this question among the two genders.

Differences in Age group. There were no significant differences.

3.4 Willingness to give data

When it comes to willingness to provide their data, automatically anonymized, to train the deep learning technique in translating the original patient report into the simplified one, 89.1% answered with “yes”. 9.5% answered with “no” and the missing 1.5% said, under the following circumstances. Circumstances named were if they were getting money for it, or it depends on what they are suffering from (1), data safety (1) and, that it depends on the demand of the data (1).

Differences in gender. There were no significant differences regarding this question among the two genders. The mentioned circumstances were solely named by female participants.

Differences in Age group. We found significant differences regarding willingness to give data among the different Age groups. In our statistical analysis. Age group 3 was most willing to provide their data with 93.8 %, who answered with yes, followed by Age group 2 with 87.5% and Age group 1, where only 85.4% answered with yes. It was also only age group one, where the circumstances, as discussed above, were named.

3.5 Interest in who is using data

We asked the patients about their general interest in who is using their data. 64.2% said, that they are generally interested in who is using their data. 35.8% said that they are not interested in who is using their data.

Differences in gender. There were no significant differences regarding this question among the two genders.

Differences in Age group. There were no significant differences regarding general interest in who is using their data among the three age groups.

4 Discussion

4.1 Our research

In our study we examined the impact of simplified patient reports on both understanding and levels of concern among patients undergoing radiologic investigations. To investigate only the impact of the simplification, levels of understanding and concern after reading the simplified version was compared to their levels after reading patient reports in their usual format. In the following, we will discuss the changes that resulted from patients perception of their understanding and their levels of concern, as well as some other questions that participants were asked in the survey. These questions were if the patients are generally interested in who is using their data, if they would provide their patient reports for the development of a text simplification software in the medical domain and, if they were interested in getting their patient report simplified for free in future.

4.1.1 Understanding

In our study, we found a significant difference in subjective levels of understanding after reading the original and simplified/ structured patient report. The overall understanding, across all patient reports that were used, improved to highly significant (p=0.000) after receiving a patient-centered report with a structured format, that included lay definitions and not complicated report filled with medical jargon and an inconsistent format.

Similar outcomes could be shown in another study, that analyzed understanding improvements after participants received lay definitions to their EHR with *NoteAid*. [74] Comprehension also improved significantly.

After reading the original patient report 47.8% of the participants said, they did not understand it, only 1.5% percent said they did not understand after reading the simplified one. The percentage of participants who felt like they did not understand anything decreased by 46.3%. Not understanding one´s own patient report results in strong patient disempowerment, poor understanding of the situation and dissatisfaction among patients. . These effects can be better managed by using simplified patient reports, that are targeted to the patient's level of health literacy instead of the usual format and medical jargon.

In addition, our research showed, that compared to 7% after reading the original patient report, 79.1% of participants reported understanding everything, that was in the simplified patient report. That means 72.1% more patients stated that they understood everything after receiving the simplified version of the report. Another study, which analyzed the different levels of understanding of their participants after receiving patient-centered reports showed similar results: Levels of understanding increased significantly. [75]

Unfortunately, todays typical patient reports are handed out in a language that is difficult to understand for medical laypeople. The terms used in these reports are usually not targeted to the patients, but rather to other medical colleagues. The medical jargon is used because it is important to precisely and effectively transfer information among medical professionals. This patient report is not meant to result in patient enlightenment.

Because the currently used patient report format has its justification, it will be important to provide another patient-oriented report in order to involve the patient in the decision-making process. It would take a lot of time for radiologists to manually rescript patient reports, in order to make them more understandable for the patients. That is why the version, that is handed out to the patient at the end of a hospital stay or after an investigation needs to be translated automatically into a patient-centered report. This would be time saving for the physician, who does not have to rescript the report and also to the patient, who does not have to search for the information online or wait for another appointment to have the results explained. Fortunately, technologic developments in the field of AI make this possible.

Increased understanding of patient reports can have various positive effects on patients. Patients, who receive understandable summaries tend to know what the next step is in management, better. [75] If they do not understand their own report, patients are dependent on other specialists to have it explained to them. Sometimes they have to wait for days for an appointment until they have the opportunity to talk to such a specialist. This waiting time can be uncomfortable and leads to anxiety and uncertainty. This can result in the well-known “Doctor Google” phenomenon.

Unfortunately, the medical information, that patients find on the internet often is unreliable and of strongly varying quality. [64] This certain degree of misinformation and anxiety can have a lot of negative consequences, as recently experienced by health care personnel in the COVID-19 pandemic.

Through the project of SimplifAI, we want to change these circumstances. We focus on two important questions:

- how can we reduce the impact of medical misinformation of patients and
- how can we empower patients to become more aware of their health status and participate more fully in their care?

Studies have shown, that when medical reports are written in lay language, patients can prepare better for appointments and they are more engaged in their healthcare. [76] These challenges can be tackled by using AI solutions in the field of natural language processing (NLP). We aim to solve a real-world problem and drive the digitization of healthcare, especially in the clinical and medical domain.

Informing patients with up to date individual and understandable reports can be seen as a big chance in improving patient participation and engagement. Written summaries can help the patients gather reliable information, and thus, improve their level of health literacy. The patients can prepare for appointments of discussion with their primary care physician and through that improve the outcome of communication. All this, like various studies have shown, can positively influence disease outcomes and patient satisfaction, through reaching a higher level of patient empowerment.

4.1.1.1 Effectiveness of the simplification

As reflected in our study the effectiveness of the simplification can vary among different reports. Some are easier to understand and result in a higher degree of comprehension among the patients, some are still difficult to understand even after being translated. Regarding the original reports, we found no statistically significant changes in levels of understanding. Across all original patient reports participants stated poor understanding after reading it. This is probably due to the difficult medical terms, used in each of the original patient reports and also the poorly understandable structure, as discussed above.

Regarding differences in understanding of the simplified patient reports, we did find significant changes among the different patient reports. Although through the simplification, for each of the 5 reports, understanding improved significantly, for some improvement of understanding was bigger than for others. This is probably due to the length and the number of explanations used in the reports.

Patient report 1 showed the best outcome of understandability. Compared to patient report 2 who showed worse understanding, patient report 1 was generally shorter. It contained fewer medical terms, that needed to be translated (patient report 1: 3 translations, patient report 2: 6 translations) and the translations were easier to understand. For example patient report 1 simplified contained the following explanation: Schlaganfall = Plötzliche Unterbrechung der Blutzufuhr zu einem Teil des Gehirns aufgrund eines Verschlusses oder Risses einer Hirnarterie. Patient report 2 contained a more complicated explanation of the following medical term: Lungenembolie= Die Behinderung des Blutflusses durch einen Embolus im Lungenkreislauf. In this context for example, the wording „Verschluss oder Riss einer Hirnarterie“ may result in better understanding than the wording “Embolus im Lungenkreislauf”.

These changes lead to the conclusion, that simplification of medical texts is not the full scope of the solution. The full scope would be to provide the patients with all necessary explanations they need to understand the text and also the simplification. It is about providing an explanation that truly is understandable to a medical layperson itself and also to provide the patients with further resources, so that possible gaps in understanding can be closed and surrounding knowledge can be acquired.

4.1.2 Level of concern

Our study showed, that finding understandable information results in overall lower levels of concern and anxiety overall. Especially in cases, where the results of examinations are not concerning, like in the case of patient report 1, where the text simplification resulted in a highly-significant decrease in levels of concern. This level of concern can be seen as appropriate in this situation. Higher levels of concern would be inappropriate and can have, in combination with poor understanding, negative effects, as previously discussed.

Surprisingly, levels of concern were generally lower after reading the simplified patient reports compared to the original one, even in the case of rather concerning patient reports. This can be due to that better understanding closes the gaps on what was NOT found, whereas these gaps are not closed so easily in the case of a hard-to-understand patient report. A similar study has shown, that a difference in risk perception can result after reading patient-centered radiological reports, even though risk probability knowledge was the same. [75]

In those comparisons, where no significant changes resulted in level of concern, as in the case of patient report 4, it is likely due to concerning findings that were made. In some cases, the simplification may result in an elevation of the level of concern, as the patients interprets the understandable version in the right way- as a concerning finding. In other patients the higher degree of understanding simply results in a lower level of concern, as knowledge gaps are closed, and patients perceive these new found facts as calming instead.

If one looks specifically at the case of the patient report 5, levels of concern did not change significantly. This may be due to the difficulty of of the patient report, even after the simplification of the text. Through simplification comprehension improved significantly, but there remained a part of the participants who still only understood half of it or nothing at all. This means that in cases where findings with lay definitions are still difficult to understand, we should focus on giving patients the ability to educate themselves further, so that they receive a satisfying level of understanding across the board.

Significant decreases in levels of concern resulted in the cases of patient report 1, 2, and 3. Patient report 1 resulted in a dramatic decrease of levels of concern. The median level of concern after reading the simplified version of patient report 1 was at 0 (not concerned), compared to a median level of concern of 3 (intermediate-high level of concern), after reading the original version of the patient report. The two effects previously discussed have not been cancelled out but amplified. Levels of concern have been appropriately lowered due to correct interpretation of the results and due to better understanding. Both resulted in a decrease of levels of concern.

Overall, we can conclude that two effects come into play regarding the changes in levels of concern when patients receive simplified patient reports. Firstly there is a trend towards appropriate levels of concern and secondly a trend of lower levels of concern after receiving understandable results and closing knowledge gaps. These two effects seem to depend on how understandable the simplified version is. They are responsible for a decrease in patient concern levels across all reports. For the individual report, this means that in less worrying findings, patients can be reassured, and an unnecessary high level of concern can be avoided. Whilst in the case of worrying findings, the personal characteristics of the patient determine whether the level of concern increases or decreases.

4.1.3 Other relevant outcomes of our survey

Interest in free simplification of patient reports. In our study, 90.5% of participants were found to prefer a simplified version of the patient report for themselves. Better information about one’s own disease is one of the key motivators to self-management of the condition and to adhering to treatment. If patients understand the treatment decisions and are part of it, they can better participate in their own health.

Providers for DL training. In our study we found, that 89.1% of the participants would be willing to provide the text corpus of their patient report for training of the artificial intelligence. Anonymization of the patients’ data contained in the patient report is an important condition for patients in order for such to happen. Since medical data is very sensitive the process of anonymization demands special attention. If the data for learning of the AI is anonymized properly permission of usage will be given by the patients, much more readily.

Since the number of training texts for the AI is crucial, one focus should be on the collection of medical data in a safe, secure and anonymized way, that projects such as simplifAI can progress and text simplification software can be used in everyday medical practice.

In our study we found that the younger participants were less willing to provide their data for DL-training, than the older groups. This may be because younger participants do not experience health issues or chronic illnesses as often as older participants and therefore might not see the advantages of improving the health care system in this way as necessary as the older participant do.

General interest in data usage. In our study, 64.2% of the participants, who were asked about general interest in data usage (by the Question: “Are you interested in who is using your data?”) answered with “yes”. This outlines the importance of clear communication to the patients, who is using their data, and if it is transferred in an anonymized way.

4.1.4 Limitations

The study was conducted in only one place, Graz, where the general population has a very high level of education. One might find that understanding could be distributed differently in other areas with lower levels of education. Most of the data was collected in a medical emergency department and therefore the patients may have been younger than the normal hospital population.

Comprehension was recorded in 3 degrees, which were all subjective to each patient. There may therefore be differences between subjectively perceived understanding and objectively ascertainable understanding.

4.2 AI and Patient Empowerment

Why are todays patient reports not simplified and uniformly structured? One of the most important reasons why this has not yet become daily practice is, that it would take a lot of time, for example radiologists would need to write down their findings in a patient-centered form, with a lot of manually added explanations in each report. Artificial intelligence (AI) could have a tremendous impact on time management. Deep learning-based approaches of NLP can automatically translate medical texts into simplified texts, that are targeted to a patient’s level of health literacy and understanding, with no extra time need from medical professionals such as radiologist, as in the example above.

Time is a big issue in the day to day practice in the medical profession. Often patients find themselves discharged to quickly and with too little information or discussion. Healthcare professionals spend a large portion of their work time typing up findings and performing administrative tasks. As the number of patients in hospitals rise along with the age in general population, there is a proportional drop in time doctors can spend on each patient. The numbers of medical professionals are not rising to meet the demand, and this leaves the health system facing a big challenge. Health care professionals have a need for assistive systems that allow for the saving of both time and energy, that can then be better spent of personal interactions with patients.

The aim of implementing AI in medicine in the big scope is to outsource work that does not require personal involvement automatically, and therefore allow for the saving of time and using it more effectively. The challenge of today’s medicine involves every subspeciality and leads to a rise of many different concepts, that might help in overcoming this challenge. The concept of Patient Empowerment does not only have the benefit of saving the physicians’ time but it allows many patients to be involved in their health care. If patients are able to access their own health care portal, know how to find information they need, take part in health improving activities and are willing and able to actively self-manage their own disease not only time can be saved.

It is important to overcome time-challenges in medicine by pushing the development and use of assistive systems, like AI-based work-assisting tools, in future. With the help of EHRs, deep learning approaches would find the necessary text corpus to practice and learn on translating medical texts. In this context patient reports must become accessible for deep learning techniques to find this necessary corpus. Unfortunately, especially in the healthcare and the clinical domain, DL techniques are rarely used yet, as they lack available open data, which is mainly due to privacy concerns. This is especially true for German-language clinical data.

With the **simplifAI** project we want to overcome these issues and apply text simplification for German-language clinical reports with a special focus on radiological reports to empower patients to take a more active role in managing their health, while respecting their privacy.

We want to achieve a reliable time- and cost-effective method to enhance patient empowerment, across all medical fields. It is therefore important to extend the schema to other medical fields, so that it can be used to save time and add value to the health care system in its totality.

4.3 NLP use in Radiology

As already discussed, one big potential of NLP algorithms in radiology is the simplification of radiology reports for medical layperson to foster patient empowerment. But there are various other potential areas in radiology, where NLP algorithms can be applied in future.

Information extraction. NLP models can analyze radiology reports and extract important information from it. This information can be used in various scenarios. For example teaching cases can be found by simply identifying cases, where a certain diagnosis or finding was made. The information extracted by NLP algorithms can also be used in retrospective studies. In one study the presence of thromboembolic and relevant incidental findings was successfully analyzed retrospectively. In this way, NLP algorithms can be used to help answering important clinical questions. [77]

Analyzing opinions to smoothen workflows. NLP algorithms can be used to extract a specialist´s opinion out of a given text. This enables one to determine the severity of findings in a report, investigate further and initiate contact with referring physician. Areas such as triaging and managing the patient initially can be made easier for health care personnel.

Classification and topic modeling. NLP algorithms are not only able to connect specific cases to certain topics, but they are also able to identify possible topics for certain cases. NLP algorithms can automatically separate a big number of cases into a finite number of topics. These topics can then be analyzed separately, giving important clues to further research potentials. Cohorts for future clinical research can be found in this way, patient reports can be organized and big corpuses of data can be found for deep learning techniques. [78]

4.4 AI in Radiology except NLP

Since the first computers were introduced, modern technology revolutionized work in radiology. Computed tomography and MRI as well as picture archiving and communication systems (PACSs) led to improvements in diagnostics and workflows in modern radiology. Especially in the last years, improvement of artificial intelligence, especially with deep learning techniques, offered the field of radiology another step into improving radiologic work.

A field, where AI are being used in todays practice and where they have shown benefits in various studies is in the interpretation of radiologic images, assisting a radiologic specialist´s work. Images can be analyzed by AI and, as with texts, compared to other images that show similar pathologies. The analysis of radiologic images can be very accurate because the AI can see slight differences in darkness and other small changes, that the human eye might miss. These possible pathologies can then be marked and analyzed by specialists.

In very specific situations, studies have shown, that a completely AI-based analyzation of specific investigations can be of comparable or even better quality than interpretations made by specialist radiologists. One of these cases was a deep-learning AI used for segmenting and classifying optical coherence tomography. [79]

Although single studies were able to show that AI can have comparable results to physicians, it is important to note that AI will often be pushed to their limits in atypical situations, where the physicians expertise are then needed. These situations may lead to significant errors and therefore the supervision of radiologists is still required. Specialists agree that such supervision will most likely be necessary in future as well.

It is important to recognize both the strengths and weaknesses of AI in radiology to integrate them appropriately. It is also important to educate medical professionals about the nature of artificial intelligence, not only how to get results but also how to avoid errors. This background information can be crucial to implementing these technologies effectively in all fields of radiology in future. Through that, specialists can save time in the future, train and be more precise in the assessment of radiological images to offer a better care for their patients. [80]

4.5 Acceptance of AI in medicine

In general, most medical professionals have a positive attitude towards the use of AI in medicine in the future. Perceived benefits include higher efficiency, assurance of quality, and time saved for clinicians that can be used for personal interaction. Many professionals state that they are willing to use AI in their practice. There is a lack of training in the proper use of artificial intelligence and of knowledge surrounding it which leads to physicians being incapable of using it well. AI can be used optimally, if training of AI use for physicians grows as with the areas in which it can used or applied.

Although many positive features of AI use in medical fields are recognized by professionals, as previously discussed, there is still a lack of trust amongst specialists using it. This is due to the high error rate, imperfect reliability, poor results in unexpected situations and also the operator dependence of AI used in practice. The unpredictability of results and lack of personal communication that comes with AI are still features that can be confidently granted only by physicians. AI is therefore not able to surrogate physicians, although it does reach comparable results in specific situations. It may, however, be used as an effective supportive tool by the physician. AI should rather become a partner than a competitor in future. [81]

Most patients have similar thoughts about AI use in medicine as health care professionals. Many tend to have a positive attitude towards its use, but they do want it to be combined with the care of medical professionals. Privacy concerns, perception of professionalism and attitude towards modern technology define the patients’ attitude towards AI-tools.

Ongoing education and enlightment about its potential benefits, privacy-safety and how the technology is being used are necessary to advance trust in AI to a higher level. [82]

4.6 EHRs in future

In our study we also examined the portion of participants that already have used their EHR system, and which system they used. Most of the patients, that were using their EHR, used ELGA. In our study, the portion of participants that used their EHR system was 34.3%. The portion was slightly higher than in other studies evaluating EHR use. In literature, the use of EHR systems is similarly low, with around 15-30% of the population using their EHR. [38] As mentioned above, besides barriers to use, such as digital literacy skills and poor navigation on EHR service sites, content displayed in EHRs plays an important role in patient acceptance and can lead to higher rates of use. [38]

The adapted content in our research was the patient report. Since doctor´s notes are a valued component of patient portals, improving their understandability has a big potential of improving the EHR and also patient education and health literacy itself. Today's patient reports mainly function as communication between two specialists. They often are written in language, that is difficult to understand for medical lay-people, and are often unstructured and do not contain information that would be helpful for patients.

Patient-centered patient reports should therefore consist of both patient-centered vocabulary that is easy to understand and provides further explanations, and a uniform and well structured format. Structured patient reports should include diagnosis, prognosis and management. [83]

Our patient-centered version of the patient report included another important structural element: the reason for the investigation as patients often find themselves in uncertainty why an investigation was done. Other features commonly seen in daily practice such as problem lists and medication lists, are less preferred among patients.

This structure would positively influence patient-centeredness and collaboration, which in turn leads to higher satisfaction and empowerment. Uniformly structured patient reports would make it easier to use them in research and other academic interests. It would also decrease the chance of communicational errors and forgotten parts of the reports.

This patient-centered version of their patient report would then be uploaded into EHR systems, such as the ELGA. Since patients always have access to their own medical records it would make it a lot easier for them to take part in diagnostic and therapeutic decisions, as well as disease self-management. Decisions and questions can be communicated effectively from patients to doctors and vice versa, via one of the tele-management tools that can be connected to the EHR.

Patients can also find content specific hyperlinks, which provide them with reliable and complete information about the disease they are suffering from or the findings, that were made. These educational resources would then be understandable for the patients and help them to enhance their knowledge about their disease and help them to prepare for important treatment decisions with their doctor. The more informed a patient goes into shared decision making discussions, the more effectively good decisions can be made.

These interventions would help physicians save some of the time used to educate their patients and help distribute the responsibility of educating patients to themselves rather than solely relying on the doctor. Patient engagement would be facilitated for the physicians, since many could have higher levels of motivation after being well-informed about options and treatment plans.

4.7 Conclusion

PE is a concept that can significantly reduce the burden on the medical system in the future. Among many other possibilities for implementing artificial intelligence (AI) in medicine, DL techniques of NLP can create added value to the health care system. By making patient reports easier to understand and incorporating EHRs, patients can be provided with a desired feature and understanding can be significantly improved, subjectively. The translation of findings can also prevent unwarranted concern, and generally remove anxiety from patients who feel disempowered from hardly understandable medical texts.

In the future, work should be done to make artificial intelligence safer and more error-free, and to bring privacy issues to the forefront and communicate them clearly. With better availability of medical text-passages from patients, DL techniques of NLP can be further improved to generate better automatic medical text-simplification. Further work can attempt to objectively measure patient understanding and thus more objectively demonstrate the influence of translation.

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