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Data and Information Problems in Health Care and How Creative Methods Might Solve Them

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Abstract. This paper discusses the concept of *data* and *information* and highlights the problems associated with their usage in healthcare. While data refers to facts and statistics collected for reference or analysis, information includes the context provided to data to gain meaning. Healthcare professionals use the information obtained from data to improve patients' health status and satisfaction. Nevertheless, the value of information depends on the data and how it is presented. As a result, many problems can arise in the collection and processing of data and the provision of information. In this paper, these are called data and information problems. One possible approach to reduce such problems in the future could be to use creative methods. To initially address this idea, exemplary keyword research was carried out, and examples are presented in this paper.

Keywords. Data Problems, Information Problems, Health care, Creative Methods

1. Introduction

The word *data* as described by the *Oxford English Dictionary (OED)* means "facts and statistics collected for reference or analysis [and] the quantities, characters, or symbols on which operations are performed by a computer" (1). Data is typically not useful on its own, but only after it is further analyzed and structured into information. For example, documenting daily temperature does not provide any information because there is no context. It could be *any* data from animals, humans, or machines. It is not until the data is put into context, e.g., measurement of a week, age of the person, weight, and health, that it is possible to extract information from the data. It can then provide meaning to a particular group of people. The word *information* is defined by *A Dictionary of The English Language* as "notice, news or advice communicated by word or writing."(2). The correlation between data and information can be visualized with the information pyramid (3). However, Capurro, among others, points out that the meaning of the terms *data* and *information* "can only ever be understood within the framework of a specific

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discipline"(cf.(4)). An important area in which data is produced, processed into information, and trans- mitted, is healthcare. Healthcare professionals can use the given information from the data, for example, to improve patients' health status or satisfaction (cf. (5,6)). However, the information can only be as valuable as the data provided. Using a specific example, the transfer of care transition records (CTR) in Germany, many problems with data and information become apparent. The CTRs usually include many nursing-relevant facts about a patient, e.g., patient main data, care problems, or medication. They differ in their semantic and syntactic provision. There are also incorrect, incomplete, or missing CTRs, which nursing staff have to deal with, resulting in increased administrative work. Therefore, the CTRs do not always fulfill the expectations of the care staff (complete and error-free) (7). That suggests, from the perspective of nursing professionals, the demands and needs for on- time delivery of correct and complete nursing-relevant information have only been met to a limited extent. This issue can be described as a data and information problem. A data problem because not all relevant data is collected and processed equally for all nursing facilities, and an information problem because the content provided is not presented in such a way that it has the maximum utility value for caregivers. Similar problems can be found in other projects or research.

The application of creative methods such as User-Centered Design (UCD) or Design Thinking has shown promising results, especially in the development and evaluation of software and hardware in healthcare (8–10). This points to the fact that the iterative involvement of stakeholders in software development is becoming increasingly significant, if not indispensable. The research group dealing with CTRs (7) used observations and questionnaires to better understand the target group's needs. Even though these methods alone do not make a creative method, they are the starting point for further iterative creative processes. The question arises to what extent creative methods are already used to solve data and/or information problems. This paper focuses on the question of how researchers deal with data and information problems in healthcare and what role creative methods might play in this process.

2. Method

For an in-depth analysis, the terms *data* and *information* were analyzed, and the conceptual explication and inductive procedures were considered. An initial keyword search was conducted on PubMed with the search terms "data" OR "information" AND "design" AND "health care" (in title and abstract) in the last five years (2018-2023). For the review process, two reviewers screened the papers independently and categorized them into (1) "data and information problems present" and "creative methods" used to solve them" or (2) exclusion. After this process, the reviewers discussed their results and decided on a list of relevant examples for this paper. Additional papers are to be analyzed and discussed in a scoping review.

3. Results

After an initial keyword search, 1.239 papers were found. Due to the high number of papers, it was decided to start the reviewing process with the first 100 papers of the search output of PubMed. Two reviewers read the abstracts independently and divided them

into the two defined categories. The results were then presented, and any differences were discussed. In the end, the most relevant examples were chosen for this paper. The most relevant papers are defined as the ones that clearly describe a data or information problem and what as well as how the creative method was used to solve it. Three examples were exemplarily selected: 1. One example points out that supervising anesthesiologists benefit from good situation awareness during an operation, but accessing or exchanging information about multiple patients can be challenging (11). This could be interpreted as an information problem as multiple patients' information cannot be provided in a usable form. The re- search used a user-centered design process based on the ISO 9241-210 combined with a rapid contextual design framework and semi-structured interviews. These creative methods were used to solve the information problem of accessing or exchanging information of multiple patients. The output of the research is an interface concept for a head-worn display. 2. Another paper focuses on displaying health record information (12). In this case, too, there is an information problem because the display of the given information is not optimized for efficient human information processing, as the display can cause information overload and contribute to clinician errors. This research used formal design methods, a seminal design theory, and a systematic and iterative process to design reusable widgets. These creative methods were used to solve the information problem of an overload of electronic health record information contributing to clinician errors. The research output is a patient information display with modular graphical components (widgets). 3. Evaluating new health information technology needs realistic testing scenarios to ensure they provide value and accurate feedback. However, obtaining realistic patient data to support these evaluations is difficult due to, e.g., the risk of reidentifying patients (13). In this case, a data problem can be construed as the collection of needed data is hindered. This research used the user-centered design method to identify tasks and develop user groups, also named personas, to gather requirements through interviews and focus groups. Here the research group tried to solve a data problem, as patient data is needed to evaluate new information health information technology. The output of this research is a five-step process to create highly structured and realistic synthetic patient data.

4. Discussion and Conclusion

Data can only be helpful when it is structured into information and put into context. Therefore, data collection and processing are essential in providing valuable information for care professionals. Four examples illustrate the difficulties when the data and information are not user-centered. It was found that creative methods such as UCD and Design Thinking were used to solve the emerging problems. It might seem obvious that these methods are used to develop a user-centered visual product such as web or app interfaces or other displays to tackle the information problem. However, creative methods can just as well be used strictly in a conceptual way. It would be interesting to investigate how such methods can be used to solve data problems, such as developing a framework for providing synthetic data. By resorting to creative methods, it is possible to analyze and integrate the data and information needs of specific target groups and to take these into account at the earliest possible stage of development. Yet, there is still a lack of established knowledge about data and information problems and the application of creative methods to solve them, which points to a potential research gap. To fill this gap,

further research on innovative methods and their integration into data collection and processing is needed.

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