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DATA SHARING AND REUSE – OPINIONS AND ATTITUDES OF PEOPLE WITH ONCOLOGICAL DISEASE: A NARRATIVE REVIEW

Partilha e Reutilização de Dados - Opiniões e Atitudes da Pessoa com Doença Oncológica: revisão narrativa

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ABSTRACT

Objective: Identify opinions and attitudes of people with cancer regarding sharing and reuse of health data.

Method: A narrative review was conducted by searching articles in the MEDLINE (PubMed) and CINAHL (EBSCO) databases, including qualitative and quantitative research studies, no time or language restrictions applied. The reference lists of each selected article were also analysed and a manual search was performed to include potential additional studies.

Results/conclusions: In general, people with cancer demonstrated a great willingness to share their health data; had some concerns, such as data privacy and security, discrimination, or misuse; were less likely to share data with government institutions and commercial entities; did not consider necessary to renew consent for future research, and would like to be informed of the most important results.

Knowing these attitudes and opinions may contribute to public and political debate, as well as the development of an appropriate legislative framework.

KEYWORDS: Health data; Data sharing; Opinions and attitudes; Oncology.

RESUMO

Objetivo: Identificar as opiniões e atitudes da pessoa com doença oncológica relativamente à partilha e reutilização de dados em saúde.

Método: Revisão narrativa através da pesquisa de artigos nas bases de dados MEDLINE (PubMed) e CINAHL (EBSCO). Foram ainda analisadas as listas de referências bibliográficas de cada artigo selecionado e realizada uma busca manual para incluir potenciais estudos adicionais.

Resultados/conclusões: De forma geral, as pessoas com cancro demonstraram uma grande disposição para partilhar os seus dados de saúde; apresentavam algumas preocupações, como a privacidade e segurança dos dados, discriminação ou a utilização indevida; eram menos propensos a partilhar dados com instituições governamentais e entidades comerciais; não consideraram necessária a renovação do consentimento para investigações futuras e gostariam de ser informados sobre os resultados mais importantes.

Conhecer estas atitudes e opiniões poderá contribuir para o debate público e político, bem como para o desenvolvimento de um quadro legislativo apropriado.

PALAVRAS-CHAVE: Dados em saúde; Partilha de dados; Opiniões e atitudes; Oncologia.

Introduction

Health data translates into biological, clinical, screening, administrative, or patient registry information. These are routinely collected and shared between doctors, nurses, hospitals, laboratories, public health departments, and other information networks[1].

Data sharing can take place within the same institution, between different public institutions, or between public and private institutions, i.e. it can involve hospitals, universities, and industry; in turn, data reuse can be defined as the subsequent use of a dataset collected and shared by researchers other than those who will (re)use it[2]. In recent years, many health initiatives related to data sharing have emerged. Some examples include GIFT--Cloud (development of new medical imaging methods), Personalized Consent Flow (new data sharing consent model), 1+ Million Genomes Initiative (European genome database), and Pediatric Cancer Genome Project (pediatric cancer genomic sequencing)[3,4].

Sharing and reuse of health data are becoming increasingly important in clinical research and cover a wide spectrum of scenarios, namely, monitoring the quality of hospital services, analyzing population health needs, or verifying the effectiveness of new treatments[5].

Research supported by health data could improve patient-centered care through the development of precision medicine, with a greater understanding of disease etiology and phenotypes, treatment effectiveness, and healthcare cost[6]. It can also improve the reproducibility and transparency of clinical research, decrease impact of publication bias, develop health knowledge, inform decision-making, contribute to generating new research hypotheses, avoid duplication of efforts in data collection, reduce unnecessary costs and provide information on social inequalities in health at global, national, and local levels[7,8].

Previous studies showed people broadly support data sharing for health research, but this support is neither unanimous nor unconditional[9]. People express as motivation the contribution to advances in healthcare and the hope of future benefits for their health, such as better diagnosis and treatment; however, they express some concerns and conditions for sharing, highlighting data security, transparency, information, and trust[6,10,11,12]. On the other hand, while universities and public health research institutions have people's trust, the use of health data for commercial research is viewed more critically by both patients and general population[5,10,12].

In oncology, sharing and reuse of health data is particularly important due to the increasing number of new cancer cases, and survivors, but also due to the social stigma that this diagnosis represents. A study conducted in Germany in 2022 shows that the vast majority of people with cancer accept making their clinical data available for biomedical research purposes, as long as data protection standards are met (including in foreign countries) and consent is renewed at regular intervals. Moreover, most people agree to give up the right to their data if it brings them research benefits[13]. Another study conducted with cancer patients reports that concerns related to health data sharing focus on lack of transparency, awareness, and control of data[1].

There are some literature reviews about the opinion and attitudes of the general population on the sharing and reuse of health data, and there are some articles about the opinions and attitudes of people with cancer, but, to the best of our knowledge, there are no literature reviews in this specific area of health. Thus, we conducted a narrative review, with both qualitative and quantitative studies, with the aim to identify the opinions and attitudes of people with cancer regarding the sharing and reuse of health data, in order to contribute to public, political, and legislative debate.

Method

Given the above, the objective of this study was to identify the opinions and attitudes of people with cancer regarding the sharing and reuse of health data, to answer the research question "What are the opinions and attitudes of people with cancer regarding the sharing and reuse of health data?". We believe that knowing the attitudes and opinions of this group of people regarding this topic will contribute to informed public and political discussions, as well as the development of an appropriate legislative framework.

Thus, a narrative review of the literature was carried out, with a search for articles in the MEDLINE (PubMed) and CINAHL (EBSCO) databases. From our perspective, this methodology presents itself as the most appropriate for the development of this work, as it provides a broad view, from different perspectives, on the subject addressed.

Primary and secondary studies, both qualitative and quantitative research, were stipulated as inclusion criteria, without time and language restriction, to be a comprehensive search. The search was carried out on 17 June 2024. The search terms were sought in the title and summary of the articles and Boolean operators were used to optimize the effectiveness of the search, as shown in Table 1. The bibliographic reference lists of each selected article were also analyzed and a manual search was carried out to include potential additional studies. Duplicate articles were removed and all others were evaluated by title and abstract to decide on their inclusion for analysis in this work.

Table 1. Search strategy

PUBMED	
1	patient OR person
2	attitude OR view OR perspective OR opinion OR willingness OR perception
3	"health data" OR "medical data" OR "clinical data"
4	sharing OR "data sharing" OR "health data sharing" OR "secondary use"
5	cancer OR oncolog*
6	1 AND 2 AND 3 AND 4 AND 5

Results

Search strategy identified 35 articles, however, after reading the title, abstract, and full text, only 12 were included in this review.

All articles are primary studies, developed between 2007 and 2024. Five are qualitative with focus groups[1,14,15] or interviews[16,17], and seven are quantitative[13,18,19,20,21,22,23]. The vast majority included people with, or survivors of, various types of cancer, except for two studies where one included only women with breast cancer[23], and the other included only people with head and neck cancer[17]. Regarding the geographical area where these studies were developed: two were developed in Europe, one in Germany[13] and one in Belgium[16]; one was developed in Australia[20]; and the remaining nine were developed in the United States of America[1,14,15,17,18,19,21,22,23].

Discussion

The themes that emerged after analysis of the studies were: general availability for data sharing; concerns about data sharing; sharing with other research teams, institutions, and/or companies; consent renewal; communication of results; motivation for data sharing; and data to be shared.

General availability for data sharing

Analyzing the articles, we found participants showed a broad willingness to share health data. Some studies report that all participants agreed to share their health data: both with medical staff and with government cancer registries[15], with the original research team, and with other research teams[16].

When not all participants are willing to share their data, the willingness to do so remains very high or high, with percentages of 96.7% willingness for biomedical research purposes[13], 94% willingness to share unidentified human data with non-profit doctors and researchers[20], 88.4% of people allowed their tissue sample to be used for research[21], 76% of people allowed if the data was not identified and 60% if the data was identified[23] and 71% were willing to share unidentified medical data[18].

One of the studies[19] concluded that people with cancer were more willing to share and reuse their health data than people without cancer, even when genetic information was included. According to Köngeter and collaborators[13], this great willingness of people with cancer to share health data for research purposes occurs because they may have already benefited, or still expect to benefit, from research results.

Concerns about data sharing

Despite the broad willingness to share health data, participants expressed some concerns.

Most of the studies analyzed showed that participants were concerned about the privacy and security of their data[1,13,15,16,17,18,20,21,22,23]. Some of the participants feared some kind of discrimination in employment or health insurance[1,14,18,21,23,] others feared misuse by criminals or for purposes other than clinical research[13], others expressed concerns about identity theft or collective harm to the community[1], with some expressing a desire to be able to control which data is shared[1,15,16].

Sharing with other research teams, institutions and/or companies

Participants in the study by Jones and collaborators[14] were largely comfortable sharing their data with doctors, between hospitals, with insurers, and with pharmaceutical companies, to improve care for the general population and themselves. Similarly, majority of participants in the study by Peppercorn and collaborators[22] supported the use of their biological products for research into other types of cancer, and different diseases or to use research techniques rather than cloning.

However, in a substantial part of the studies analyzed, participants showed some divergence with the total sharing of their data[1,13,16,17,18,20,21,22,23].

In the study by Köngeter and collaborators[13], in Germany, most participants said they would like to make their data available to research teams from other countries, as long as data protection standards were comparable to German standards. Only a minority said they would make their data available only for national research.

Some studies showed that participants strongly supported sharing their data with academic medical institutions, universities, or non-profit organisations[13,18,22,23], but agreed less with sharing with government institutions[18,22,23], even less with commercial entities[13,18,20,23] or with the public[18,22].

In the study by Raj and collaborators[1], some participants expressed discomfort with the possibility of their health data being commercialized, due to loss of ownership and the fact that companies could make money from personal and private health information. Participants in the study by Spector-Bagdady and collaborators[17], with people with head and neck cancer, also expressed some reservations about the commercialization of their health data for clinical research, such as who would buy and use the data (government, pharmaceutical industry, or advertising) and how the profits would be used, however, they showed a positive attitude if the profits were reinvested in clinical research.

However, in the study by Broes and collaborators[16] the majority of participants regretted the lack of collaboration and data sharing between researchers for commercial reasons, with only a minority of participants preferring sharing and use by academic researchers over pharmaceutical companies, due to commercial interests.

Still, a study conducted in the United States a few years ago by Helft and collaborators[21] showed that, overall, study participants were less likely to agree to the use of their biological products for future research that did not involve their type of cancer or by other researchers, but two-thirds of participants agreed to the use of their biological products for the development of a new tool or new treatment for profit.

Consent renewal

Analysing the articles, it became evident that the majority of participants understood that it was not necessary to renew consent for future research with their data, with only some fluctuation in percentages. Only in one of the studies did the majority of participants express the need for renewal at regular time intervals[13].

Thus, in the study by Köngeter and collaborators[13] almost half of the participants preferred consent renewal for data sharing at intervals of 3 or 10 years, one-third preferred consent with unlimited validity, and a small minority preferred consent renewal with each new use of their data.

In the study by Broes and collaborators[16] less than half of the participants expressed the need to be informed about the sharing and reuse of their data as a way of increasing transparency or simply out of curiosity, with the majority not considering this information necessary. In the same way, most participants were confident in having an independent ethics committee decide for them on the reuse of data for additional research[16].

In the study by Peppercorn and collaborators[22] about one-third of participants said they wanted to be asked for new consent whenever their data was used to develop new research. Similarly, only some of the participants in Franklin and collaborators[18] study mentioned the need for additional information about each new investigation before data sharing took place, as well as subsequent communication of the results found. Also, the study by Helft and collaborators[21] showed that a clear majority of participants agree with future research, using their stored biological products, without the need for new consent, with only a minority expressing the desire to grant new consent.

Communication of results

In some of the studies analyzed, participants expressed a desire to be informed about the most important results of the research that used their data, as a data sharing requirement[13], as a way of increasing transparency[18] and, if the findings had an impact on their health even if there was no treatment available or it was too early to know if the research results were valid[21].

Motivation for data sharing

When investigating what could motivate data sharing, studies highlighted social issues such as altruism, where data could benefit other patients with or without cancer and society in general[13,14,15,16,18,19,22,23]; or personal issues such as the possibility of benefiting their own clinical situation[13,14,18,23], the opportunity to receive a report with the results of the research and the possibility of receiving financial incentives[18].

Data to be shared

Only one of the studies[15] addressed the topic of what data cancer registries should contain and what data cancer survivors would like to obtain from the registries.

Thus, participants mentioned that the data that registries should contain would be: the long-term effects of cancer and its treatment, such as symptoms, side effects, quality of life and functioning; cancer incidence, treatment and survival data; comorbidities; quality of care; and, nutrition. On the other hand, data that people with cancer expected to obtain from the registries included symptoms, side effects of cancer and its treatment; survival statistics; new treatments, and clinical trials; quality of care; cancer prevention strategies such as nutrition, physical activity, cancer screening and awareness; and, support information such as support groups for the patient and their family, community and financial resources[15].

Conclusions

From the literature consulted, we conclude that people with cancer showed a broad willingness to share their health data, however, they had concerns about data privacy and security, misuse of data, and discrimination in employment or with health insurance. Participants expressed greater agreement with sharing with academic medical institutions, universities, and non-profit organizations, and less agreement with government institutions or commercial entities. In general, participants did not consider it necessary to renew consent for future research with their data, but some would like to be informed of the most important results. As a motivation for sharing data, participants believed it could benefit other people, society in general, and ultimately themselves. They also said that the data they would like to share or retain from previous sharing would be information about cancer and its treatment, quality of care, prevention strategies, and support information.

Although all the studies analyzed had people with cancer as participants, the samples are very heterogeneous as they cover different types of cancer, as well as different countries, policies, cultures, and health systems, which implies different access to them. On the other hand, the number of articles analyzed was small. Perhaps if we had searched for articles in more databases we would have found other relevant studies on the subject, but the ones we consulted are the most relevant in the medical and nursing fields.

Despite the described limitations, we believe this work could contribute to public and political debate and to develop an appropriate legislative framework. However, given the continuous development of science and society, it is crucial to carry out further studies that always include people with, or survivors of, different types of cancer.

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Conflict of interest

The authors declare that there is no conflict of interest.