On the Power of Data Visualization in Transforming Patient Decision-Making

Sobre o Poder da Visualização de Dados na Transformação da Tomada de Decisão do Doente

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Palavras-chave: Aconselhamento Genético; Compreensão; Participação do Paciente

Data plays a central role in modern healthcare, forming the foundation for diagnosis, treatment plans, and patient care. However, the true potential of data lies not just in its collection but in its effective interpretation and communication. Healthcare data visualization emerges as a powerful tool, transforming complex medical information into clear, actionable insights driving patients' informed decision-making.

Genetic data exemplifies a particularly intricate form of information in healthcare. Accurate understanding of this data is crucial for patients to integrate risk perception into decision-making processes. This can lead to informed decisions regarding follow-up strategies. A prime example is understanding the risk of cancer associated with hereditary forms of cancer predisposition. For instance, pre-surgery knowledge of carrying a breast cancer predisposition variant can influence surgical strategy,[1] or numerical data presentation strategies can influence risk perception of hereditary cancer.[2]

Genetic counseling plays a vital role in this process. It equips patients with the knowledge to grasp their potential cancer risk. It empowers them to derive personal meaning from this information and make autonomous, informed decisions regarding genetic testing, cancer screening, and preventive measures.[3]

Traditionally, healthcare professionals have relied on oral descriptions to convey a patient's cancer risk associated with a specific gene. Data visualization, such as graphical representations, offers a promising complementary approach to enhance communication and risk understanding.[4] Nevertheless, the factors influencing the interpretation of genetic data remain largely unexplored within the Portuguese population. This knowledge gap is particularly relevant considering Portugal's historical context of lower educational attainment. As of 2023, over 50.5% of the population lacks a secondary school diploma.[5] Given this demographic landscape, it is crucial to tailor data visualization techniques specifically for the Portuguese population.

Our ongoing research aims to investigate Portuguese patients' preferences for visualizing genetic cancer risks. While a pilot study with medical genetics patients identified popular graphical representations, it also revealed a subset who preferred verbal explanations (unpublished work). This highlights the need to consider diverse communication styles within the Portuguese healthcare ecosystem. By conducting research that is specific to the Portuguese population, we aim to optimize data visualization and storytelling tools for effective communication and patient empowerment, ensuring these tools are well-suited to this unique healthcare landscape. While our focus is on medical genetics, we believe that the insights gained from this research can be valuable for other healthcare fields in Portugal that require effective communication of complex information to patients.

AUTHOR CONTRIBUTIONS

DN: Writing and critical review of the manuscript.

CAS: Conceptualization, writing and critical review of the manuscript.

All authors approved the final version to be published.

COMPETING INTERESTS

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