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CONFERENCE ABSTRACT

Psychosocial needs and preferences of individuals with hereditary cancer syndromes: Practice implications for the healthcare responsiveness

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Eliana Silva[1], Pedro Gomes, P. M. Matos, E. R. Silva, João Silva, C. M. D. Sales

1: Faculty of Psychology and Education Sciences, University of Porto, Portugal

Introduction

Individuals carrying an inherited mutation for hereditary cancer syndromes usually have a long-term risk management process, requiring a responsive healthcare system. Most studies about their perceived quality of the services used patient-reported outcome measures through quantitative studies. Although valuable, they did not provide an in-depth understanding of individuals' experiences and perspectives about the healthcare system. Thus, this study aimed to describe the individuals' experiences of care and to identify their perceived psychosocial needs and preferences to improve healthcare responsiveness.

Methods

This is a qualitative study entailing 13 interviews with Portuguese adults. Participants had one of the following hereditary cancer syndromes: Hereditary Breast and Ovarian Cancer Syndrome, Lynch Syndrome, Hereditary Diffuse Gastric Cancer Syndrome, or Familial Adenomatous Polyposis. The protocol interview was developed in collaboration with individuals with hereditary cancer syndromes and healthcare professionals. Most participants were male (n = 7; 53.8%), ranging in age from 22 to 53 years old. Interviews were analyzed using thematic analysis.

Results

Four main themes emerged from the individuals' interviews: (1) quality of clinical information; (2) clinical relationship; (3) psychological support, and (4) healthcare organization processes. For each theme, participants described their needs, preferences, positive and negative aspects of each dimension of care, and provided suggestions about possible improvements to the healthcare services.

Discussions

To the best of our knowledge, we conducted the first study about the psychosocial needs and preferences of individuals with several hereditary cancer syndromes from the moment they decided to undergo genetic testing until the long-term management phase risk.

Conclusions

According to our results, individuals appreciated being informed about their clinical condition and available preventive approaches, and involved in a humanized, accessible, and responsive

healthcare. This first-hand knowledge of mutation carriers' experiences is particularly valuable to healthcare professionals and settings become more responsive to these individuals that need clinical surveillance during their entire lives.

Lessons learned

The psychosocial needs and preferences that mattered most to mutation carriers also include their families and are not limited to their clinical condition but also to their personal identity. Individuals have different needs along with all the specific phases of the adaptation trajectory of carrying an inherited mutation that increases the risk for cancer.

Limitations

Although data saturation was reached, our study participants' experiences may represent little diversity because they are mainly associated with one healthcare center. Another limitation is the retrospective nature of the data collected, given some participants had undergone their genetic testing or surgery a long time ago.

Suggestions for future research

Our findings suggested the need for more research within identity concerns among the mutation carriers for a better understanding of their identity preferences with its associated implications in terms of clinical communication and healthcare services organization. In addition, we made several practice implications that may contribute to the healthcare services to become more responsive to the mutation carriers' psychosocial needs and preferences.

Keywords

hereditary cancer syndrome; genetic counseling; risk assessment; qualitative analysis; patient experiences of care; patient and public involvement