PhD in Media and Communication Studies

"Screaming in the Desert:

A qualitative study on the beliefs and expectations of patients with rare tumours in their interactions with medical specialists"

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Abstract

People with rare diseases tend to exhibit a strong need for information and often demonstrate significant commitment to their medical care. Their determination typically leads them to actively seek out and comprehend information, share their experiences within their communities and use experiential knowledge to complement theoretical medical knowledge. Patients with rare diseases are considered to be among the most active and resilient in the health sector which can be explained by their ongoing struggle for attention, for earlier diagnosis and better treatment.

In this context of rare diseases, patients appear to play an increasing vital role in generating and disseminating medical knowledge. Over the past two decades, the integration of experiential knowledge with scientific knowledge has fostered collaborative processes between patients and healthcare professionals. This co-creation of knowledge emphasizes the practical, daily experiences of patients, influencing clinical evaluations and treatment approaches.

This situation, where patients hold crucial information about managing symptoms and the effects of medication, typically leads to expectations for balanced relationships in which patients' knowledge and experiences are valued and recognized. It is meaningful to examine whether such a balance in role-giving and role-taking is achieved during medical consultations, especially in the dynamics of information sharing and decision-making.

This research addresses the communication processes between patients and health professionals, specifically among patients and parents of young patients with rare tumours, a subgroup within the 6000 to 8000 rare diseases. By conducting semi-structured interviews with patients and professionals and analysing content from disease-specific and pre-diagnoses blogs and forums, the study aims to identify patients' expectations and preferences during medical consultations and understand how these align with healthcare professionals' approaches.

Among the key findings, the study indicates that patients and parents of young patients generally prefer active and collaborative roles in their interactions with health professionals, with a lesser preference for passive roles. The degree of trust significantly influences these preferences. High mutual trust is associated with both collaborative and passive interaction preferences. Reduced trust tends to lead to a preference for active roles, where patients seek more control over the interaction. Furthermore, proficiency in digital skills and disease knowledge seems to enhance patients' inclination towards active interaction patterns. The study extends the concepts of 'congruence' and 'incongruence' to describe the alignment between expected and actual interaction experiences. Both collaborative and passive patterns often lead to congruence, while active interactions can result in incongruence if patients feel restricted in adopting their preferred role. A lack of trust regarding professionals' skills and expertise reinforces the preference for active roles, pushing patients to test the limits of the doctor-patient interaction.

This research enhances understanding of the interaction preferences among patients with rare tumours, of the dynamics of congruence and incongruence in patient-professional interactions, and of the importance of experiential expertise in shaping preferred interaction roles.

To better meet patient expectations, the study also proposes the use of personas that encapsulate patient preferences and characteristics. The developed personas can serve as tools for healthcare professionals to understand and address the unique needs of patients with rare tumours and their caregivers, ultimately enhancing the decision-making process and information provision.

Keywords: rare tumors – information needs – patient-doctor interactions - trust