

EXTENDED ABSTRACT

Between cat content and YesweCan!cer: Digital media repertoires for disease management of young cancer patients

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Between cat content and Yeswecan!cer: Digital media repertoires for disease self-management of young cancer patients

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1. Introduction

Young adults with cancer are particularly challenged while managing their disease. On the one hand, they must consider the various (long-term) side effects of the therapy (Bukowski et al., 2015; Stüwe & Pawlowski, 2021), and on the other hand – because their problem is not typical for their age – they hardly find any psychosocial support within healthcare and private settings (Sodergren et al., 2017; Koehler et al., 2020). They, therefore, must deal with their illness independently as part of disease self-management (DSM) (Linder et al., 2017). Digital media play a central role in the DSM of young adults with cancer (Reifegerste & Linke, 2020; Slater et al., 2017), but there is a lack of research on the structures and functions of their media repertoires. This study, therefore, links the concept of media repertoires (Hasebrink & Popp, 2006) with that of disease self-management (Lorig & Holman, 2003).

2. Theoretical background

Disease self-management encompasses various strategies for coping with diseases (Barlow et al., 2002). In the context of cancer, it includes measures from the domains of disease-specific information, healthy behaviors, medication, and physical symptom management, dealing with physical effects, psychological impact management, and others, such as spirituality (Cuthbert et al., 2019). Previous research on digital media use among young adults with cancer only highlights single aspects of DSM, such as information seeking (Aggarwal et al., 2020; Clercq et al., 2020), and only considers particular media types separately. This is problematic with regard to the use of diverse digital media by young cancer patients for DSM.

In contrast, the approach of media repertoires, according to Hasebrink & Popp (2006), emphasizes the importance of considering the entire media repertoire from a user-centered perspective. It thus addresses the interplay and interactions of media (Hasebrink & Hepp, 2017) and avoids a ‘single media bias’ (Hasebrink & Domeyer, 2012, p. 758).

Both the media repertoire approach (Hasebrink & Popp, 2006) and the concept of DSM consider the users (and not the medium), the completeness of the media/strategies (and not an individual) as well as their functions (and not only their use). Hence, they are linked within the present study. The media repertoire

approach (Hasebrink & Domeyer, 2012) provides the framework in which the six strategies of DSM are integrated as specific needs of young users with cancer. In detail, we investigate exploratively: how media repertoires of young cancer patients are composed with regard to components and indicators of use, how these are used for the strategies in DSM, and which functions contribute to the different media fulfilling the respective strategies in DSM.

3. Method and data

For the analysis, $N = 12$ young adults ($n = 4$ men; $n = 8$ women) who had cancer between the ages of 22 and 34 were interviewed about using digital media during their cancer therapy to identify which specific functions they fulfil in disease self-management. For a contextualized repertoire analysis (Hasebrink & Hepp, 2017; Merten, 2020), the qualitative interviews were combined with egocentric network maps for visualisation. The interviews were analysed using qualitative content analysis, creating a deductive-inductive category system that considers both theoretical findings and the openness of qualitative methods (Schreier, 2012).

4. Results

Overall, digital media have a high relevance in the repertoires of young cancer patients. For most young patients, the repertoire maps show that the internet (mainly via Google), WhatsApp, Facebook, Instagram, TikTok, video chat programs, and video and music streaming portals play a decisive role in their DSM. In addition, cancer-specific apps such as Yeswecan!cer and cancer-specific forums can also be found. Regarding the usage indicators, four types could be distinguished along the diversity and intensity of usage. Low users, moderate users, high users, and intensive users differ in terms of the diversity of media and the intensity of use for the functions of the DSM.

Furthermore, the results show that young cancer patients use digital media very diversely for the strategies of disease self-management according to Cuthberg et al. (2019). Complementing the classification of Cuthberg et al. (2019), social support as a strategy and public relations as another function of media use in DSM could be identified. For the strategies information, social support, and dealing with psychological effects, media use was particularly intensive, using diverse media components. In contrast, the other strategies were mentioned only sporadically.

As assumed, the functional characteristics of media determine how they can be used for DSM. For example, it can be decisive that an offer can be selected independently of time and place to adapt to the current mood or needs. On the other hand, the content that can be accessed or created is particularly important when it comes to information gathering, distraction, or helping others who are affected. Within social support, young patients choose which medium to use according to their communication partners' characteristics or their habits.

5. Discussion

The high relevance of digital media for the DSM of young cancer patients shows that applying the approach for this topic may provide an important addition to media repertoire research. Taking a user-centered approach, it is possible to un-

derstand which needs the use of the (evolving) media repertoire can (and cannot) meet. From a communication science perspective, the step-by-step method and flexibility of the media repertoire approach prove to be very adaptable to DSM. Therefore, combining both perspectives also allows a transfer to other topics, populations, and media contexts.

Regarding practical implications for health science, our research underlines that the elevation of specific usage functions is needed to identify central features of the media repertoires. Their functions reveal that digital media primarily cover those areas of DSM that are not (or cannot be) fulfilled by (medical) health care or the social environment. In that, digital media are primarily used for information, social support, and dealing with psychological effects in the acute therapy phase of young adults. This aligns with the fact that media are used more intensively and diversely when the social environment cannot fulfill these functions. Thus, media use plays a crucial role in terms of compensation and, in the sense of the uses and gratifications approach (Katz et al., 1974), serves as a functional alternative for fulfilling the needs for distraction, structuring, or exchange. To ensure a focus on those affected by diseases and their needs, research should not only be theory-based but also participatory (Wright, 2021).

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