



Experiences of living with genetic cancer risk: an online study

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Who we are

We are University researchers working on a project exploring experiences of novel research and treatments within cancer care. As part of this work we are considering what it is like for people to undergo screening and monitoring for cancer when they have not been diagnosed with the disease itself. To find out more about this, we focused on people's experiences of living with a genetic condition that causes them to be at high risk of developing bowel cancer.

We wanted to explore what it was like to live with a high risk of cancer over time, and a good way to do this was to study online blogs written by those with genetic bowel cancer risk. Blogs are used by individuals to describe events and emotions, usually through many separate 'posts' written over time. We found that blogs written by those with a particular type of genetic bowel cancer risk, called Familial Adenomatous Polyposis (FAP), offered important insight into how people manage genetic risk. This might be through medical procedures. For example, many bloggers had experienced the removal of all or part of their bowel, or other organs, to reduce their risk of cancer.

What we did

We searched for blogs written by those with FAP using the search engine *Google*, and found eight that met our search criteria. The blogs varied in the number of posts they contained, and the amount of time they covered. The shortest was written over 4 months and comprised 10 separate posts, the longest was 47 months with 144 separate posts.

We wanted to make sure that we acted ethically when using online blogs in our research. Online blogs are publically available, though contain personal descriptions of emotions and relationships, and sometimes photos and phone numbers. We contacted the eight bloggers over email or Twitter, and asked for permission to use their blog posts in our research. In cases where we could not get in touch with the author, we have not used their exact words in our research. We have not used any of the bloggers' real names.

What we found

We read and compared all the posts written by the eight authors in their blogs, while keeping in mind what other research on cancer risk has told us. We found that three issues captured the experiences written about by bloggers: identity, community and care.

Identity

Bloggers described how they came to know about their high genetic risk of bowel cancer, and what this knowledge meant for their sense of self. Through these descriptions, many of the authors discussed that bowel cancer (risk) had always been in their family, and had stories of their parents and grandparents being diagnosed with cancer. Because their own risk of bowel cancer was so high, all but one of the eight bloggers had undergone bowel surgery. Bloggers had powerful memories of these major operations, which in most cases had taken place during childhood. For many, these operations had caused them to feel unwell in ways that impacted daily life, for example by making it difficult to digest food, or causing them to need the toilet more frequently.

Community

The eight bloggers described several motivations for writing about their experiences in online blogs. An important reason was to connect with others including friends and family, but also other people living with bowel conditions. The bloggers described what it is like to live with genetic cancer risk, but also what it is like to live with the consequences of surgery. Those who'd had bowel surgery at the time of their blog wrote about their experiences in hospital and in some cases posted photographs too. They shared advice about living with a 'stoma' (a bag worn on the outside of the body to collect waste, following the removal of the bowel). They also shared experiences of living with other effects of bowel surgery, including low levels of iron in their blood, and tiredness. Such experiences are shared across a range of health conditions, and the bloggers did not only address their blogs to other people who had FAP, but to those who had experienced similar surgeries for a different reason, or who were living with another health condition over a long period of time.

Care

We found that by sharing advice about surgeries and living with a long-term health condition, bloggers seemed to be caring for their readers. This might be through offering positivity to others in similar situations, or simply by providing practical advice about coping with the long-term effects of major surgery. Writing online posts can also be seen as a way that bloggers cared for themselves. Some described that blogging allowed them to connect with others sharing their condition, and also gave them a space to write down and share feelings of sadness or frustration. This might be after negative encounters with healthcare professionals, or when they felt anxious about medical appointments and monitoring for cancer.

Why is the study important?

This study adds to sociological research that has discussed how genetic risk is experienced by individuals day-to-day. Different aspects of genetic risk, including fear and anxiety, but also positivity, may come to the fore over time. This might be prompted by specific medical appointments, anniversaries of the deaths of loved ones, or by feeling unwell.

Our research has described how these particular experiences are written about online, and the meaning of this for individual bloggers. Online blogs enabled authors and readers to make connections with other people with similar experiences, and to care for others and themselves.

The full article is available to read (free of charge) here: <https://www.tandfonline.com/doi/full/10.1080/14636778.2018.1469974>



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