debates and issues

Cancer survivors providing care: a call for a new approach

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The provision of psychosocial care to cancer patients has been explored in detail in the literature. The objective of the present article is to show the need for a methodological approach in exploring the social dimension of care. The study sample comprised 15 ovarian cancer participants in long-term remission, who were included in the ‘Vivrovaire’ study. We employed a qualitative approach based on semi-structured interviews. Results showed that these patients were both recipients and providers of care. We highlighted the importance of a methodological approach that considers care as a dynamic and social process in order to analyse the relational dimension of care.

key words ovarian cancer • long-term remission • care • qualitative methods

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Introduction

The provision of psychosocial care to cancer patients is a question explored in great detail using quantitative and qualitative methods in the cancer-related psychosocial literature. It shows that there is a need to improve care in psychosocial interventions and support for patients’ family and friends (Swash et al, 2018; Tolbert et al, 2018). Authors have also noted heterogeneity in unmet care needs among cancer survivors.
(Arch et al, 2018) and emphasised the importance of carer support for ‘post-traumatic growth’ (Calhoun and Tedeschi, 2014).

The nature and efficiency of the social support that cancer survivors receive has been studied using various methods, and in-depth interviews with patients (asking them about their health care) have been shown to be a good way of examining ‘patients’ perception of their health problems’ (Fitzpatrick and Boulton, 1994). Yet, to date, no published study has explored the support that cancer survivors provide to family and friends during remission.¹

The study

This article discusses findings from the French ‘Vivrovaire’ study, which explored the ‘social dimension of care interactions’ (Keating and Eales, 2017) and patients’ and their relatives’ adjustment to new social roles during remission. It focused on the relational dimension of care (Hughes and O’Sullivan, 2017) and on social support (the social relations between patients and carers), using methods suggested by Catt et al (2017), and taking social interactions and positioning as indicators.

The Vivrovaire study was a multidisciplinary national programme funded by the French League Against Cancer that focused on survivors of ovarian cancer (OC) in long-term remission. It was a multicentre case-control study implemented in 25 cancer centres of the French cooperative group the National Group of Investigators for the Study of Ovarian and Breast Cancer (GINECO). The study’s main aim was to evaluate chronic fatigue in patients (and their physical sequelae), as well as their levels of anxiety and depression. The sample comprised 318 patients in long-term remission from OC and a control sample (n = 318). Vivrovaire also included qualitative research conducted in cancer centres in Bordeaux, Caen and Lyon, whose overall objective was to study the impact of OC on patients’ quality of life (QOL). In this article, we describe the qualitative sub-study conducted in Lyon. This focused on survivors’ trajectories and analysed survivors’ accounts of their illness.²

We conducted semi-structured interviews with 15 women in two different phases; first, exploratory (fairly unstructured) interviews were conducted (in 2016) to capture patients’ accounts and help identify issues or themes that we had not previously considered; and, second, in 2017, more structured in-depth interviews were conducted based on themes from the exploratory interviews.³ Our final sample comprised 15 OC patients in long-term remission recruited in Lyon as part of the qualitative dimension of Vivrovaire; participants had been diagnosed with OC an average of 9.6 years previously. Fifteen exploratory and nine structured individual interviews were conducted. (Six patients chose not to participate in 2017.)

Findings

Analysis of the 24 interviews highlighted three main themes: bodily and physical issues arising from the experience of OC and treatment; changes in social life; and perception of the OC experience. We found that OC patients in long-term remission may take on the role of ‘care provider’ for their family and friends, often performing practical duties and providing psychological and moral support
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to their family and friends faced with difficult life situations, such as domestic conflict or divorce. While most patients probably provided such care long before their OC occurred, they appeared to experience it very differently during remission. They sometimes found it hard to help their family and friends in daily life, either because they wanted to focus on their own personal objectives and priorities, or because, having experienced cancer, the daily problems of their family and friends appeared meaningless to them. In particular, the end of treatment seemed to have caused a ‘second biographical disruption’ (Bury, 1982), leading to an ambiguous perception of their own identity as women who were neither ill nor healthy. This was reflected in their remarks about the persistence of medical screenings, memories of the disease and fear that it might recur. In contrast, for their relatives, the end of treatment probably implied the end of the disease. Laypeople often believe that surviving cancer is, at least partially, due to patients’ coping skills, rather than only the efficacy of diagnosis and treatments. Seeing the patient heal thus produced a form of admiration among patients’ close relatives, who perceived the survivor as an example of strength and resilience, and assigned her a specific identity status and social roles that she could find rigid and restrictive.

Discussion

Research on post-traumatic growth has shown that adopting a new perspective on life may have a positive impact on an individual’s QOL, enabling patients in remission to cope with uncertainty after ‘a biographical disruption’. Qualitative and quantitative analyses have also been conducted to identify cancer survivors’ and their relatives’ psychosocial needs at the interpersonal level, and to assess how well these are met through the social support that survivors receive from their family and friends. The very concept of ‘care’ has thus almost always been conceived and measured with a focus on the resources that people receive to support their individual adjustment to the disease.

In addition to individual adjustment, however, cancer patients in long-term remission also deal with an important social adjustment that has been little studied by researchers to date. Living with cancer may have profoundly modified survivors’ own life expectations and priorities, as well as how they experience the social roles that their family and friends attribute to them. The social expectations of friends and family may have been reinforced by a belief that the disease is definitely cured and that the cancer survivor is strong and resilient. This experiential gap between survivors and their families suggests the need for a broader psychosocial approach that assesses the quality of social interactions and the redistribution of social roles after cancer.

In Vivrovaire, we examined the social support provided by patients to their family and friends in order to inform future studies exploring the provision of psychosocial care to cancer survivors, as well as to ensure that the importance of exploring situations where patients are both recipients and providers of care is included. The importance of giving back what one had received was spontaneously mentioned by many (60 per cent) interviewees: surviving cancer was perceived as a gift in exchange for which they had to make a counter-gift. For some, this counter-gift – owed to society in
general – was a kind of ‘mission’ that gave their life a different and sometimes deeper meaning after the biographical disruption.

As psychosocial studies have shown, the equal exchange of resources is rarely respected, especially in the family context: the gift/counter-gift calculation is commonly refused and negatively judged. Asking a family member for support without offering something in return is not blameworthy from a moral point of view: the individual helped is in debt without necessarily feeling the obligation to give back. The large experiential gap between cancer survivors and their family and friends found in the Vivrovaire study meant that cancer had very different consequences for their social positions and roles. While survivors felt indebted to the society that had saved them from cancer, they reported that their family and friends continued to ask them for support – as before the disease – without feeling the need to offer them a reciprocal exchange.

In their role as carers, some of these women were deprived of any social acknowledgement of the psychological distress that they may experience in caring for their family and friends, especially if they have new personal priorities and life expectations. This may especially apply to those in long-term remission, whose medical care is no longer a key element of their lives and where their social network has forgotten about the disease (more quickly than the patient herself). We should stress that not all cancer survivors feel distress about supporting their family and friends. Indeed, providing support may strengthen some survivors’ identities, help them face the uncertainties of being in long-term remission and help them find a new social position in society so that they can ‘give back’ what they feel they have received. In this way, some survivors may become ‘expert patients’ (Tattersall, 2002).

Conclusion

Our main goal in this article is to highlight the importance that should be given to social interactions and to patients’ and their relatives’ adjustment to new social roles during remission. We also want to emphasise the lack of a specific methodological approach for considering the relational dimension of care. In future, we hope that research will not only assess whether social support meets the needs of individuals (or couples), but also consider caring and social support as forms of social interaction and positioning so that the consequences of cancer for social relationships within the patient’s network can be investigated.

Finally, while the size and heterogeneity (in age, time since diagnosis and other factors) of our sample and our research method do not allow us to generalise our findings, we nevertheless believe that this very heterogeneity is what makes it possible to consider care as a dynamic, mutual and social process, observable over time and over patients’ trajectories. We hope others concerned about the QOL of cancer survivors will find our study useful in guiding their work.

Notes

1 A few quantitative studies (Walsh et al, 2005; Moore et al, 2015; Park et al, 2016) have explored patients’ roles, especially as parents, in daily life but none has focused on this issue for survivors.

2 Patients included in the study met the following inclusion criteria: they had received optimal treatment (surgery and chemotherapy) for OC, irrespective of cancer stage at
diagnosis; they were \( \geq 18 \) years old; they had no documented relapse for at least three years after initial treatment; and they had no other cancer. Anonymous personal identifiers were used and informed consent was obtained from all participants.

3 Interviews were conducted and recorded by a social science researcher in locations chosen by the patients. For analysis, and to apply the iterative process needed for the thematic analysis of the 2016 data, we used the Computer Assisted Qualitative Data Analysis Software (CAQDAS) package ATLAS.ti, identifying themes using the constant comparative method (Glaser and Strauss, 1967). Coded categories were directly and inductively derived from raw data and then systematically compared in order to construct meaning. We also took into account the three analytical levels noted by Bertaux (2016) in the patient trajectory analysis, focusing on: (1) the reality lived and perceived by participants (historical and empirical reality); (2) how they retrospectively thought about their trajectory (the narrator’s psychological and semantic reality); and (3) how they talked about their trajectory in their interaction with the researcher (the discursive reality of the narrator).

4 Consistent with classical gift theory (Mauss and Evans-Pritchard, 1967).

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Conflict of interest
The authors declare that there is no conflict of interest.

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