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Implementing long-term follow-up after pediatric cancer: ethical tensions and survivor perspectives

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Introduction

The late effects of treatments after pediatric cancer constitute a significant concern. However, childhood cancer survivors (CCSs) are not always aware of the risks involved. Information and further follow-up for CCSs are therefore crucial (1).

In France, long-term follow-up (LTFU) care for CCSs has been driven by pediatric oncologists, medical specialists, and GPs and conducted in either LTFU clinics or the physician's offices. However, some survivors are not followed.

Aim of the study

Identify the **needs and expectations** of survivors regarding LTFU

Identify and analyze the central **ethical tensions** that the implementation and organization of LTFU may raise.

Method of the qualitative survey

- **qualitative survey** based on the SALTO cohort. SALTO offered a follow-up consultation to all people treated for pediatric cancer diagnosed between 1987 and 1999 in the French Rhône-Alpes region.

- **empirical ethics approach**, based on the perspectives of survivors. **845 questionnaires** with open-ended questions were sent to the participant of the SALTO cohort (> 168 completed). **48 in-depth interviews** aimed to explore the after-cancer experience concerning medical follow-up were conducted with volunteers.

Results

I. Different Perceptions of the Cancer Episode:

How the cancer episode is perceived has an impact on how the follow-up is approached. People for whom cancer is an episode of the past may be less concerned with follow-up than those for whom cancer is experienced as a chronic condition. **However, this perception does not always correspond to the medically assessed state of health: the perception of cancer episode depends on the pathology/the perceived health status/the late effects of treatments/the existing medical follow-up, evolves in the same person according to the occurrence of symptoms related to late-effects/knowledge about the risk of late-effect/intensification or termination of follow-up, etc., fluctuates according to time of life and constraints or expectations associated with them.**

II. Different Expectations at Different Times of Life:

Needs and expectations regarding LTFU **vary significantly according to age, periods of life, and related constraints**, or to the acceptance of the medical history that sometimes evolves:

"I'm getting to a point in my life where...I had the teenage years, all of that. I was trying not to think about the sequelae, cancer that I had, and live my life like a normal person. And in fact, I've reached a point in my life where I say to myself: you've had all that you have to live with it. »

Depending on the **time of life**, CCSs may need **more or less autonomy/support in managing their medical follow-up**.

Moreover, there are **overlaps** in these periods of life, and some disruptions are sometimes caused by **new symptoms** or **new information** about the health condition. We can thus speak of the **complex temporality of after-cancer**.

III. Different Roles of Follow-Up Consultation for CCSs:

Obtaining medical information / **understanding** the impact of cancer & treatments on current health status:

"I tried to understand. Could [my current health problems] be related to [pediatric cancer]? And could it be necessary to do tests, to start things over?"

Understanding or clarifying a situation:

"It was a somewhat taboo subject in my family, so it was a bit difficult to know what happened, the exact pathway. [The doctor] gave me a good explanation; she explained everything that had happened, chronologically. "

Re-situating some elements in a life trajectory:

"I don't think I have many questions. At least, not necessarily medical ones. It's more about sharing things. It was essential, more in terms of reconnection, to 'reconsider' what I experienced. (...) At some point, you want to confront your memories with the memories of others."

Discussion

Results suggest that LTFU should be adapted to the needs and expectations of CCSs by taking into account the **complex temporalities of the post-cancer period/the impact of new information on how people view their current health status/the psychological burden** that this may represent. In this perspective, LTFU would benefit from being **co-constructed** by CCSs and all professionals involved in follow-up.

(1) Gianinazzi ME, Essig S, Rueegg CS, von der Weid NX, Brazzola P., Kuehni CE, et al. Information provision and information needs in adult survivors of childhood cancer. *Pediatr Blood Cancer* 2014;61:312-8
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