



## Educational trajectories after childhood cancer: When illness experience matters



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### ABSTRACT

With the increase in survival from childhood cancer, research has increasingly focused on the educational and professional achievements of childhood cancer survivors. Yet, if large-scale studies provide an acute description of the current situation of childhood cancer survivors, little is known about their trajectories and the social processes shaping these trajectories.

Using a qualitative methodology, drawing from a life course perspective, this study sought to describe the role of childhood cancer and its side effects in educational trajectories, as perceived by the participants. We investigated related processes of social adjustment to cancer, that is to say, choices or decisions that survivors related to the illness in the making of their career plans. Eighty long-term French childhood cancer survivors participating in the Euro2K longitudinal study were interviewed through in-depth, face-to-face interviews undertaken in 2011–2012.

There were various types of impact described by respondents of the diagnosis of cancer on their trajectories. These varied according to gender. In women, childhood cancer tended to result in poor educational achievement, or in steering the individual towards a health care or child care occupation. This was justified by a desire to return the support that had been offered to them as patients. In men, however, childhood cancer led to a shift in career plans, because of physical sequelae, or because of concerns about their future health. Paradoxically, this limitation had a positive impact in their occupational achievement, as most of these men disregarded blue-collar jobs and chose more qualified white-collar occupations. Overall, findings suggest that childhood cancer influenced educational trajectories and, thus, socioeconomic status in adulthood, through mechanisms embedded in gender norms. These mechanisms could explain gender inequalities in educational achievement after childhood cancer reported in large-scale cohort studies.

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### 1. Introduction

Medical advances over the past four decades have prolonged survival from childhood cancer. This progress has been achieved through the use of multimodal and aggressive treatments. Nowadays, about 80% of children with cancer survive the disease, but 40%

of survivors have late adverse effects (Oeffinger et al., 2006). With the increase in survival from childhood cancer, research has been growingly focused on the educational and professional achievements of childhood cancer survivors (De Boer et al., 2009). Large-scale studies conducted in Europe and Northern America have found mixed results, showing a lower, better, or similar educational achievement of survivors, compared to that of controls (Boman et al., 2010; Dieluweit et al., 2011; Gurney et al., 2009; Kelaghan et al., 1988; Koch et al., 2004; Kuehni et al., 2012; Lorenzi et al., 2009; Pastore et al., 2001). Brain tumor survivors, on the other hand, have systematically been found at risk of poorer social outcomes (Lund et al., 2011). In addition, many studies have underlined a lower educational or occupational achievement of female

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survivors compared to male survivors (Kirchhoff et al., 2011; Koch et al., 2004; Lancashire et al., 2010; Lorenzi et al., 2009; Mitby et al., 2003). However, a weakness of this body of research is that no study has included a longitudinal perspective. These large-scale studies provide an acute description of the current situation of childhood cancer survivors, but little is known about their trajectories and the social processes shaping these trajectories.

The health selection explanation, which states that poor health prevents upward social mobility, has occupied a minor place in the studies of health inequalities (West, 1991). The stunting variant of the health selection hypothesis argues that poor health during childhood may limit an individual's initial accumulation of human capital and subsequent access to higher social positions (Haas, 2006; Palloni et al., 2009). Besides the poorer academic performances due to frequent absenteeism from school during periods of illness and hospitalization, several possible mechanisms are under consideration. The interruption caused by the disease might constitute a disadvantage for interacting with peer groups, or might delay opportunities to explore personal and occupational interests. Moreover, poor health in childhood might influence educational aspirations, resulting in a reduced projection in long-term educational goals. Indeed, lifestyle choices may be significantly altered by cancer and its after-effects. Fear of recurrence and the burden of health conditions induced by treatment toxicities might influence survivors in their planning about education plans, and, therefore, might negatively affect their educational and occupational achievement.

Some studies have attempted to assess this latter mechanism through questionnaires or interviews made with young patients recovering from childhood cancer. They showed that young survivors could report a negative impact of cancer on their vocational aspirations (Badell et al., 1998; Gerber et al., 2006; Servitzoglou et al., 2008), lower professional expectations or less concrete plans for the future (Boman and Bodegård, 2004; Gerhardt et al., 2007; Servitzoglou et al., 2008), or a change in their career plans resulting from cancer (Felder-Puig et al., 1998; Servitzoglou et al., 2008). However, most of these studies were conducted during the transition from adolescence to emerging adulthood, with young survivors who had not necessarily completed their education, lacking perspective in their career and in their life course.

Through in-depth interviews with a large sample of long-term adult survivors, the aim of this qualitative study was to describe the perceived role of childhood or adolescent cancer and its side effects in educational trajectories. Drawing from a life course perspective (Giele and Elder, 1998), we retrospectively investigated processes of social adjustment to cancer, that is to say, choices or decisions that survivors related to the illness in the making of their career plans.

## 2. Materials and methods

### 2.1. Theoretical framework

In our study, we were interested in the concept of “trajectory”. In the life course perspective, this concept is mobilized to describe the sequence of social positions occupied by individuals within a period of time or within a defined domain of social life. Qualitative methods provide in-depth insight into the fabric of social trajectories, the longitudinal interrelation between events, and the social contexts in which they take form. Indeed, the life course paradigm does not deny the importance of structural forces at play. In fact, life courses are commonly seen by sociologists as the result of highly complex processes operating at multiple levels, which means to take into account the embedding of individual lives into constraints and opportunities dependent on the social positions of actors

(Mayer, 2009). In our study, in accordance with a long sociological tradition (Weber, 1978), we were more specifically interested in the action-theoretic level of explanation within these trajectories which emphasizes the meaning that individuals attach to their own actions. Hence, processes of social adjustment to childhood cancer were considered as the actions (choices, decisions, strategies) in which individuals had integrated the subjective experience of childhood cancer.

### 2.2. Study participants

Study participants were French members of the Euro2K cohort, an international on-going longitudinal study which started in the 1990s to assess adverse effects of cancer treatment. Participants in this cohort were treated for solid tumors or lymphoma between 1948 and 1985, when they were children or adolescents (<18 years old). Eligibility for and recruitment to the cohort has been described elsewhere (De Vathaire et al., 1995). Some of the original participants were excluded however, because of diagnostic errors and duplicates, and some others have been added, who were initially missed because some medical records were not available at the time of the initial cohort constitution, but were discovered during a systematic investigation of hospital archives performed afterward. In 2011, 2456 patients were considered as eligible patients (e.g., alive at time of study), of whom 1920 agreed to participate in the follow-up study.

For the qualitative arm of the study, patients treated before 1970 were excluded in order to reduce discrepancy in age and period of treatment as well as survivors treated for central nervous system tumors because of the late cognitive effects and the specific challenges they face (Boydell et al., 2008; Duffner, 2010). Among the remaining participants (n = 1389), a sample was constructed using random selection, with age at diagnosis strata (<7 years, ≥ 7 years) in order to over-represent survivors treated when they were seven years old or more, e.g., survivors who might have a more accurate memory of their illness than survivors treated at a younger age. We sent recruitment letters to 160 participants and were able to contact 97 (60.6%). Of those contacted and eligible, 80 (82.5%) participated. Six persons refused to participate and the interview could not take place in spite of agreement in 11 cases.

### 2.3. Data collection and analysis

We first made an explorative qualitative study in 2011, using life history interviews, eliciting personal narratives, with 17 adult survivors. The analysis of these interviews provided the relevant categories to conceive a comprehensive semi-structured interview guide. This explorative study also revealed a great variability in situations of childhood cancer survivors. The number of subsequent interviews was high (n = 63) in order to stratify analysis by different subgroups according to type of cancer, age at diagnosis, and physical sequelae related to cancer.

The interview guide was divided into two parts. The first part covered the history of the disease and the immediate and long-term after-effects of cancer, as well as other health problems (*health trajectory*). The second part of the guide dealt with the perceived impact of cancer on social life, and, in particular, in the educational and vocational domains (*social trajectory*). Even in semi-structured interviews, interviewers let participants articulate their perceptions and experiences freely and spontaneously as much as possible. The subjective experiences of participants were considered as central. Thus, participants were not given any indication of a positive or a negative impact, but rather were asked if they perceived any impact of childhood cancer in their life. At the end of the interview, information on parental social status (e.g.,

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