



Adolescent and young adult cancer survivors narrate their stories: Predictive model of their personal growth and their follow-up acceptance

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ABSTRACT

Purpose: Few studies have captured the unique ways in which cancer affects the growth and development of adolescent and young adult cancer survivors. This paper illustrates the daily life of childhood cancer survivors who are now adolescents and young adults, their post-traumatic growth and follow-up perceptions, adopting a narrative approach.

Methods: One thousand adolescent and young adult cancer survivors, mean age at diagnosis being 9.26 years old (SD = 4.29) and current mean age of 19.28 (SD = 2.96), were interviewed in depth using a new version of Ecocultural Family Interview–Cancer (EFI-C), which has proved to be a psychometrically reliable instrument.

Results: Post-traumatic growth was predicted directly by age at diagnosis and, indirectly, by the mediation of the health medical staff–patient relationship during the illness, hospitalization memories, and patient's narrating skills. Positive feelings towards follow-up visits were predicted by the health staff–patient relationship during the illness (Chi-Square = 2.87; df = 3, p-value = 0.41; RMSEA = 0.0001).

Conclusion: Adolescent and young adult cancer survivors who were older and had established strong relationships with health professionals at the clinic were more able to narrate their experiences, display a positive comprehension of the events with a pragmatic acceptance of the follow-up procedures.

Relationships with health professionals should therefore be monitored and improved, both during the cancer treatment and in the off-therapy period. The narrative technique allows adolescent and young adult cancer survivors to reorganize and give shape to their traumatic experience.

1. Introduction

Due to advances in chemotherapy and supportive care, about 83% of childhood cancer patients aged 0–19 years survive at least five years (Associazione Registro Tumori AIRTUM, 2017). Researchers examining the psychosocial sequelae of childhood cancer survivors have focused mainly on the negative effects of the illness, such as motor performance delays (Taverna et al., 2017), or self-esteem difficulties (Tremolada et al., 2017) that could escalate into psychopathological symptoms (Stein et al., 2008), especially if they had undergone hematopoietic stem cell transplantation (HSCT) (Zanato et al., 2017; Reinfejl et al., 2017). However, the recent literature deals primarily with the positive aspects derived from facing and overcoming such a painful experience, highlighting how some adolescent and young adult (AYA) cancer survivors are able to re-evaluate and revise their experiences, minimizing the possible negative impact on their psychological well-being; a

phenomenon known as post-traumatic growth (Zebrack et al., 2012a, b).

The recurrent thoughts, generally considered as indicators of psychopathological processing of post-traumatic stress disorder (PTSD), could be represented as the efforts of the survivors to accept the negative aspects of the experience, to rework it and to give it a new meaning, thus acquiring a sense of security and well-being (Park et al., 2010). Post traumatic growth and PTSD are two sides of the same coin, as confirmed in a recent study (Tremolada et al., 2016b). These positive consequences involve changes in three different domains: philosophy of life, interpersonal relationships and self-perception (Barakat et al., 2006; Mattsson et al., 2008; Zannini et al., 2014). The majority of AYA cancer survivors (over 80% according to the study conducted by Sumalla et al., 2009) are able to find something good even in the toughest settings, therefore managing to benefit from the illness experienced: in particular, they seem more confident, stronger,

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empathetic, mature and even more determined to achieve their goals. They mostly appreciate life, tend not to take anything for granted and are less focused on trivial everyday concerns (Mattsson et al., 2007). Even relations with others appear improved: they report deeper, more intimate and solid relationships with family members, friends and the medical staff who took care of them during the long treatment (Jones et al., 2011).

At the same time, some AYA cancer survivors have shown poor engagement in their follow-up at the hospital, influenced by socio-demographic factors and specific aspects of their illness (Barakat et al., 2012). The relationships and feelings of childhood cancer survivors towards their follow-up at the day hospital of the clinic need to be understood, especially with regard to the topics of communication and information, to explain more meaningfully the reasons for such instances of poor engagement.

Some studies have identified the following sociodemographic factors as associated more frequently with favourable personal growth: female gender (Tedeschi and Calhoun, 1996; Kamibeppu et al., 2010); presence of a marital/relationship status, higher education and income (Eiser et al., 2000; Zebrack et al., 2012a; b). Illness-related variables could be predictive of childhood cancer survivors' personal growth, such as older age at diagnosis (Zannini et al., 2014; Yi et al., 2014); more aggressive treatment; shorter space of time between diagnosis and recovering (Zebrack et al., 2012a; b; Yi et al., 2014); and longer duration of treatment (Gianinazzi et al., 2016). A positive correlation was found between social support perception and PTG (Ekim and Ocakci, 2015), confirming good social bonds and good relationships with hospital health professionals (Jones et al., 2011) to be predictive of higher PTG. Difficulty of acceptance in follow-up seemed to be related to being non-white; living at a greater distance from the hospital; being male; dependent on public insurance; being off treatment a greater length of time; and having a malignant brain tumour (Barakat et al., 2012).

1.1. Study aims and expected results

Given the recent interest in understanding potential positive effects of cancer, this study aimed to (1) examine the perceived personal growth and daily routines of adolescent and young adult childhood cancer survivors using a narrative approach based on an ecocultural framework; (2) examine the extent to which cancer-related factors (age at diagnosis, time since diagnosis, cancer diagnosis type), key socio-demographic variables (gender, age at the assessment, education status, presence of a long-term partner) and psychosocial factors (social support, relationships with health staff) predict the likelihood of young adult survivors' attributing positive outcomes to having had cancer; and (3) identify the factors that could somehow increase the acceptance and the level of tranquillity experienced by the survivors towards follow-up visits. This concept is important for adherence with AYA follow-up procedures.

Based on the literature review, we wanted to confirm an expected theoretical model identifying the main stable and modifiable factors impacting on PTG and on the level of acceptance and of tranquillity experienced by the survivors towards follow-up visits.

We expected that females (Kamibeppu et al., 2010), those who were older at the time of diagnosis, with higher education levels and who had long-term partners (Sumalla et al., 2009; Zannini et al., 2014) would have higher positive personal growth. Given that current age was seen as closely related to cognitive development achieved by individuals (Vianello, 2004), we expected this factor to influence the ability of AYA cancer survivors to rework the experience, tagging it as a positive one, thereby limiting the negative impact of the traumatic event. We expected also that positive relationships with parents, with siblings (Barakat et al., 2006; Mattsson et al., 2008) and with the healthcare staff of the clinic (Jones et al., 2011) would be closely associated with higher levels of personal growth. Having established that a positive

relationship with the hospital staff during the illness could be considered as a protective factor mitigating the ambivalent feelings caused by the visits in the ward, i.e. fear of relapse, it could be predictive of higher levels of acceptance towards follow-up visits. Another variable not shown in the literature that we wanted to take into consideration was the ability to remember and narrate episodes concerning the period of treatment; we assumed such a skill to be a natural predictor of the adolescent and young adult's ability to reprocess and to recognize the positive aspects of the illness experience.

2. Method

2.1. Participants

All eligible survivors attending the pediatric oncohematology clinic, Department of Child and Woman's Health at the University Hospital of Padua (Italy) in the period 2008–2012 were asked to take part in this project. Eligibility criteria included having been treated for cancer before the age of 18, being at least five years from the end of therapy and being currently aged 15–25 years. We excluded survivors treated for central nervous system tumours, those with learning or sensory deficits or genetic syndromes and those who were unable to complete the questionnaires autonomously (N = 123). Altogether, 230 of the 325 eligible survivors had been informed of the study and reached by phone before their follow-up visit. The 95 eligible survivors whom the researchers did not reach for the study had either changed their phone numbers; moved from their original residential locations; not had scheduled check-ups during the research period; or had no more follow-up visits scheduled at the clinic. One hundred AYAs of the 230 recruited (43.47%) were interviewed using a narrative approach. Sociodemographic and medical information are reported in Table 1.

2.2. Procedure

Ethics approval was obtained from the Hospital of Padua Ethics Committee. The day before the follow-up appointment at the day hospital of the clinic, the clinical psychologist phoned each survivor to explain what the study was about in detail and to obtain participation consent for the following day. If the survivor was less than 18 years old, the parents were contacted before talking to the participant and parental consent for participation was also obtained. Upon their arrival at the clinic, the AYA cancer survivors were given the sociodemographic questionnaire and interviewed using a dedicated version of Ecocultural Family Interview–Cancer (EFI-C) (Tremolada et al., 2012) specifically rearranged for the target population. The consent form was completed by AYAs or, for those younger than 18 years of age, by their parents.

2.3. Measures

2.3.1. The ecocultural approach: ecocultural-family interview–Cancer, pediatric cancer survivors version

Methodology adopted so far in research to study PTG has consisted of self-report questionnaires. A few studies have used qualitative methods such as written narratives (Zannini et al., 2014) or a mixed-method approach (Sinatora et al., 2017) to understand childhood cancer survivors' experiences and the influence of the illness in their daily lives. We know very little about the AYA cancer survivors' long-term adaptations to cancer—their practical concerns, their ways of dealing with the emotional upheaval caused by the diagnosis, and their use of social networks and other supports. For these reasons, we adopted the narrative approach which considers human development and human experiences as inextricably related to the context in which they occur. Adopting a narrative approach makes it possible to have a theoretical and epistemological methodology which starts with the observation that the survivor's daily routines and actions are aimed at adaptation tasks, in which multiple people participate. Such tasks are

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