

Body Image Discomfort of Adolescent and Young Adult Hematologic Cancer Survivors

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This study focuses on body image discomfort (BID) of 50 adolescent and young adult (AYA) hematologic cancer survivors (age range 15–23; 52% males). The study results were obtained through data from a self-report questionnaire: the Body Uneasiness Test. Findings differed according to gender: a greater proportion of females were in the Risk category of impaired body image than males ($\chi^2 = 5.258$, $p < 0.05$). No significant body image differences were found according to the type of diagnosis or to the length of survival. To manage survivors' BIDs and to improve their quality of life, assessing BID in AYA cancer survivors is important for identifying those who might be in need of additional supportive care or a program.

Keywords: body image, biopsychosocial approach, quality of life

Introduction

SURVIVAL AFTER CHILDHOOD and adolescence cancer has substantially improved over the past few decades, and now stands at 80% considering all diseases, and nearly 75% of patients will be living 10 years after diagnosis.¹ In Italy, the 5-year survival rate from diagnosis has improved from 72% (1988–1993) to 83% (2003–2008) and it is constantly increasing, especially for hematologic cancer diseases. There are now more than 30,000 adolescents and young adults (AYAs) aged between 15 and 30 years who survived a cancer diagnosed during adolescence (about 13–18 years), a figure comparable with that reported in other European countries.^{2,3}

However, improvements in survival implies an increase in morbidity in long-term survivors.^{4,5} Among all the late effects, body and physical alterations are reported as a major concern (percentages vary from 30% to 60%), especially in AYA survivors.^{6,7} Various diseases and their treatments, such as surgery, chemotherapy, and radiotherapy, are associated with aggressive physical and body side effects.⁸ In particular, high-dose chemotherapy and/or total body irradiation during development often involve hair loss, disfigurement, changes in body weight, growth impairment, and limitation in physical movements.^{8–10} Some of these adverse effects can lead to feelings of body image discomfort (BID) also among cancer survivors.

Developing a positive body image is a key task during adolescence and young adulthood, because it has particular

implications for self-identity, self-esteem, and social relationships.^{11,12} Experiencing cancer during adolescence is probably one of the most destructive experiences for the body and it can cause a certain degree of BID, which means negative feelings and thoughts about the whole body and its functioning and it does not only refer to physical appearance. Discomfort may also cause anxiety,¹⁰ depression and a negative impact on quality of life among young people.

Systematic literature reviews on body image of cancer survivors^{7,8} clearly showed the incongruence of research findings because of several methodological and conceptualizing biases. Specifically, the conceptualization of body image was often unclear and numerous studies did not use body image as their main focus. Moreover, the majority of scales used are not validated to examine body image (but often measure physical appearance) at national and international levels. Furthermore, the role of gender and other clinical variables has yet to be settled. Females were overrepresented and more subgroup comparisons about body image (e.g., type of cancer and length of survival) are needed. Very few studies that looked at both genders evidenced that males rated their body image better than females, one study found better body image among females than among males,¹³ whereas other studies showed no differences^{12,14–16} As far as the type of diagnosis is concerned, Calaminus et al. showed that leukemia survivors rated their body image better than solid tumors survivors without confirming any past evidence of major difficulties

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among hematologic cancer survivors.^{11,17} Some studies highlighted that negative body image experiences are most common after some years from the end of treatment.^{13,17} However, further research is needed, because none of the mentioned studies considered survivors who completed the treatment 5 or more years before (“long-term survivors”).

Thus, as the results do not offer any clear findings, it is even more important to continue to investigate the experience of possible BID among cancer survivors. This study highlights possible differences based on (a) gender: females versus males; (b) type of diagnosis: acute lymphoblastic leukemia (ALL) versus Hodgkin or non-Hodgkin lymphoma (HL/NHL); and (c) years from the end of treatment: off therapy survivors (under 5 years from the end of treatment) versus long-term survivors (5 years or more from the end of treatment). An examination and then an intervention on survivors’ body image might lead to healthcare professionals adopting health-promoting behavior and surveillance programs specifically aimed at enhancing patients’ well-being. Evidence of effective therapeutic interventions has been highlighted by some recent research, which includes psychoeducation, emotional support, peer support, and the use of coping skills.^{18,19} Proposing these types of programs may protect the survivors’ body image not only in the short term but also in the long term by also reducing subsequent related adverse emotional and social difficulties such as anxiety, depression, low self-esteem, social withdrawal, and a refusal to go to school.

Materials and Methods

Research participants

Participants were enrolled at the Pediatric Onco-Hematology Department of the Regina Margherita Children’s Hospital in Turin. Eligibility criteria were (a) ages from 15 to 23 years; (b) a diagnosis of ALL, HL, or NHL; (c) off therapy for at least 1 year at the time of the study; (d) Italian origin; (e) no cognitive impairments (e.g., mental retardation); and (f) no Bone Marrow Transplantation (BMT).

The study was proposed to all the survivors who had scheduled a medical appointment during the period of the study (from May 2012 to September 2013). After seeing a member of the medical staff, participants and their families also saw a psychologist who explained the research study that consisted in a protocol of examining the body image of survivors. Data were collected through a paper format questionnaire that took an average of 30 minutes to complete. The human research protocol was approved by the hospital’s Ethical Committee. Written informed consent was obtained from the participants or from their parents or guardians for participants less than 18 years.

Although the participants were not assisted in the filling out of the questionnaire, a psychologist was available for any questions. Clinical variables were provided by physicians through medical records.

Measurements

The Body Uneasiness Test (BUT) was used as the study tool. The BUT had already been validated with young patients with eating disorders and used with other types of patients.^{20,21} This specific instrument was also chosen in light of the concerns about body image in cancer survivors as well. The BUT has two

versions (A and B) consisting of 34 and 37 items, respectively. The A version was used for this study. The answers of BUT-A were scored on a five-point Likert scale from “never” (0) to “always” (5). Higher scores indicate greater body uneasiness. In keeping with previous validation studies, the BUT-A scores were combined in a Dichotomic Global Severity Index (*Risk* vs. *No Risk*) that suggested the possibility of clinical risks and adverse events, and it was obtained by summing all the items of BUT-A and by dividing the total by the number of items (cut off: *Risk* >1.2, *No Risk* <1.2) and in five subscales resulting from factorial analysis: weight phobia (WP—fear of being fat, eight items; e.g., “I’m terrified of gaining weight”), body image concerns (BICs—worries related to physical appearance, nine items; e.g., “I’m worried about my physical image”), avoidance (A—avoidance behavior, six items; e.g., “When I get undressed I avoid looking at myself”), compulsive self-monitoring (CSM—compulsive checking of physical appearance, five items; e.g., “I fear that my appearance may suddenly change”), and depersonalization (D—detachment and estrangement feelings toward the body, six items; e.g., “When I look at myself in the mirror I feel a sense of anxiety and alienation”). Cronbach’s alpha coefficients range between 0.64 and 0.89. The Italian version of the BUT and scoring instructions is reported in the validation studies.²⁰

Statistical analysis

Descriptive statistics were used to analyze socio-demographics and clinical characteristics. A comparison among the groups (subgroups of gender, type of diagnosis, and length of survival) was made using *t*-test analysis for ordinal variables (BUT subscales) and chi-square test for categorical variables (Dichotomic Global Severity Index). Statistical analysis was made with SPSS 20.0 for Windows (SPSS, Inc., Chicago, IL).

Results

Fifty survivors ($M_{\text{age}} = 17.7$, age range 15–23; $SD = 2.53$; 52% males) met the eligibility criteria and agreed to participate in the study. Only 20 survivors (71% participation rate) declined because they did not have time to stay at the hospital to complete the questionnaire. The age range at diagnosis was 13–18 years. Forty-eight percent ($N = 24$) of the survivors had a diagnosis of ALL and 52% ($N = 26$) a diagnosis of HL/NHL. Seventy-two percent ($N = 36$) of the survivors are off-therapy survivors (1–5 years from the end of treatment) and 28% ($N = 14$) are long-term survivors (more than 5 years from the end of treatment). All the survivors were treated according to therapy protocols shared among the centers, which adhered to the Italian Association of Pediatric Hematology and Oncology (Table 1). Overall, female survivors showed a higher negative body image than males. The differences were significant in every subscale of the BUT-A ($t_{\text{wp}} = -4.149$, $p < 0.05$; $t_{\text{bic}} = -4.171$, $p < 0.05$; $t_{\text{a}} = -2.950$, $p < 0.05$; $t_{\text{csm}} = -4.103$, $p < 0.05$; $t_{\text{d}} = -2.777$, $p < 0.05$), but the most significant differences were found in the WP and BIC subscales. Also when compared with the Global Severity Index (GSI), a greater proportion of females were in the Risk category than males (females $n = 9$; 39%; males $n = 3$; 12%; $\chi^2 = 5.258$, $p < 0.05$). No significant differences in body image were found between leukemia and lymphoma survivors or between the off-therapy and long-term groups (Table 2).

TABLE 1. SURVIVORS' SOCIODEMOGRAPHIC CHARACTERISTICS (N=50)

Variable	Category	N (%)
Gender	Male	26 (52)
	Female	24 (48)
Diagnosis	ALL	24 (48)
	NHL/HL	26 (52)
Family condition	Intact family	31 (62)
	Divorced	7 (14)
	Other	12 (24)
Living conditions	Alone	8 (4)
	With parents	42 (96)
Level of education at the time of the study	Lower secondary	8 (16)
	Lyceum	14 (28)
	Technical	5 (12)
	Professional	22 (44)
Age	University	1
	Range: 15–23	Mean: 17.7, SD: 2.53

ALL, acute lymphoblastic leukemia; HL, Hodgkin lymphoma; NHL, non-Hodgkin lymphoma.

Discussion

This study examined BID among AYA cancer survivors, considering gender (female vs. male), type of diagnosis (ALL vs. HL/NHL), and length of survival (off-therapy survivors vs. long-term survivors) as possible risk factors. Despite the recognized interest of body image issues in this population, some important questions remain. First, the role of gender still needs to be clarified because of the lack of studies examining both males and females together. Second, no studies to date have examined survivors' body image according to the type of hematologic diagnosis. Third, there is no recent, unequivocal evidence about the fact that survivors' body image experience may differ according to the number of years from the end of medical treatment. In this study, we have attempted to clarify these questions to further our knowledge about survivors' BID.

Based on our results, female survivors' body image is more impaired and markedly different from that of male survivors. Females showed more fears of gaining weight and more worries related to their physical appearance than males.

These results confirm that part of the literature that highlighted female survivors as the group with major issues regarding body image.^{6,12} No differences were found in terms of BID when comparing ALL and HL/NHL survivors. This result further emphasized the fact that body image is a personal construct and is probably independent of the type of cancer diagnosis and its treatment. Also, no differences were found between off-therapy or long-term survivor groups. We may thus assume that 1 year from the end of treatment might be a sufficient time to accept possible bodily changes and to integrate a different body image.

In conclusion, cancer might affect the perception of body image more among AYA female survivors than male survivors, which may confirm the greater difficulties female cancer survivors have than male survivors. Previous studies have shown poorer quality of life, fatigue, and more feelings of depression among females than among males.^{22–24}

Our study is not without some weaknesses, such as the small sample size and the cross-sectional design. Future studies should examine the body image in a large sample to generalize the findings and should take into account potential covariates that may be related to BID (e.g., gender, type of diagnosis, length of survival, and body mass index). Despite these limitations, our study has its merits. The measurement tool (BUT) confirms the innovative nature of our study as it permits to underline some important components of body image experience, which have not been examined among AYA cancer survivors. Comparing with scientific literature, AYA cancer survivors seem to have more elevated BID values than other types of patients,^{20,21} although depersonalization, avoidance, and compulsive self-monitoring seem to be phenomena less present. Future research is needed to replicate our findings and improve the validity of this tool in examining cancer survivors' body image issues. Finally, future studies should also investigate body image among HL and NHL survivors separately, as HL survivors may have more severe late side effects because of the treatment than the other groups.

The strong clinical implications should also be underlined. AYA cancer survivors have to be considered as a target population with specific needs that require attention. Many late effects such as body disaffection can be mitigated through targeted surveillance, the adoption of health-promoting behavior, and early management/treatment.¹⁰ Unfortunately, around two-thirds of cancer survivors do not engage in health promotion programs.²⁵

TABLE 2. MEAN DIFFERENCE: BODY IMAGE SUBSCALES OF SUBGROUPS SURVIVORS (GENDER-TYPE OF DIAGNOSIS, LENGTH OF SURVIVAL)

	Males		Females		Leukemia		Lymphoma		Off-therapy		Long-term	
	(M)	(M)	t	p	(M)	(M)	t	p	(M)	(M)	t	p
Weight phobia	6.8	15.04***	-4.149	0.000	10.2	8.6	-0.717	0.477	9.1	9.5	-0.205	0.839
Body image concerns	7.6	15.1***	-4.171	0.001	9.3	10.7	-0.559	0.579	8.7	10.5	-0.669	0.507
Avoidance	1.3	3.7**	-2.950	0.003	2.4	2.3	-0.097	0.923	1.2	2.8	-1.725	0.091
Compulsive self-monitoring	2.6	5.6**	-4.103	0.005	3.9	3.3	-0.661	0.512	3.4	3.7	-0.327	0.745
Depersonalization	1.2	2.6*	-2.777	0.018	1.4	1.9	-0.874	0.386	1.5	1.7	-0.258	0.797

***p < 0.001; **p < 0.005; *p < 0.05.

AYAs should have access to support programs, activities, and places dedicated to their stage of life. It has been demonstrated that educational and supportive psychological care groups enhance self-confidence and self-esteem. Therefore, as these issues are closely associated with body image, intervention groups do have an indirect significant effect on BID. These effects are present immediately after the intervention and also several months later.¹⁰ Thus, supportive care is needed for hematologic cancer survivors to help them regain a sense of well-being of their own body, to strengthen internal and external coping strategies, and to facilitate their “return to normality.”

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