

PSYCHOSOCIAL FUNCTIONING OF CHILDHOOD CANCER SURVIVORS LIVING IN RURAL AREAS

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Abstract: High-dose chemotherapy currently used in the treatment of children with cancer may induce late effects on psychosocial and cognitive functioning in some of them. The aim of the study was to evaluate psychosocial functioning of childhood cancer survivors living in rural regions. In total, 29 children entered the study. The children were diagnosed as having cancer between 1993-1995 in a single centre. Each patient was examined 5 years after the completion of cancer therapy. The children had been diagnosed with leukemia and lymphoma (72.4%), and solid tumours. Self-report questionnaires, as well as standardized psychological test (WISC-R, WAIS-R-PL) were performed for the evaluation of psychosocial and cognitive functioning of the patients. Most of the studied cancer survivors living in rural areas did not reveal difficulties with cognitive and psychosocial functioning. In some patients, however, we observed more difficulties in verbal tasks and existing major learning difficulties. Cancer survivors living in rural areas in our region may be more unprivileged due to poor additional supporting services.

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INTRODUCTION

The long-term cure rates for childhood cancer have improved dramatically during the past four decades [5, 8, 9, 23]. This progress was achieved by enforcement of treatment protocols that included surgery, chemotherapy, and radiation, and the quality of progress in survivor rates also depended on a multidisciplinary approach to patient care, adequate hospital infrastructure, and psychosocial support for children with cancer and their families. Nowadays, more than 80% of children with acute lymphoblastic leukemia can be cured. However, children with cancer should be treated only in specialized paediatric onco-/hematology centres ensuring high quality of medical and psychosocial care. In Poland, both childhood cancer treatment protocols, and multidisciplinary and psychosocial approach to a child

with cancer are performed. Most cancer survivors enjoy long, productive lives, are well integrated into their communities, and make substantial contributions to society [3, 6, 8, 18, 19, 20, 26, 34]. Polish childhood cancer survivors also have occasion to be well adjusted to their everyday life after completion of cancer therapy.

In general, cancer survivors' quality of life concerns the assessing of their physical, psychological, social and spiritual well-being [8, 9]. The findings of several studies have suggested that survivors of childhood cancer are at risk for psychological difficulties in two principal domains: social adjustment with peers and emotional well-being [19, 20]. But according to others results, young cancer survivors as a group revealed reasonably good social and emotional adjustment [30]. Recently, the role of socio-cultural features was found to play a role in the psychosocial adaptation

after completion of cancer therapy [25, 31]. Patients living in rural areas may be less privileged in this aspect from those in urban areas. Urban-rural disparities in educational investment and in the quality of teaching and learning are widespread.

The psychosocial functioning of childhood cancer survivors are described in terms of quality of life dimensions: Cognitive functioning, Scholastic competence, Peer acceptance, Physical well-being, Future expectations, and Parents attitudes.

The aim of the study was to estimate psychosocial functioning of childhood cancer survivors living in rural regions in the above mentioned dimensions.

PATIENTS

Childhood cancer survivors living in rural areas were studied. All patients were diagnosed as having cancer between 1993-1995 and were treated in paediatric an oncematology ward in Lublin. A group of 29 childhood cancer survivors followed in the outpatient clinic (62.1% boys and 37.9% girls) were selected for the study. Each patient was examined 5 years after completion of cancer therapy. The median age at the moment of cancer diagnosis for the whole group of patients was 5.51 years with the range from 0.8 to 15.4 years. Most of the children had been diagnosed with leukemia and lymphoma (72.4%). The remaining patients were diagnosed as having other types of solid tumours. Children diagnosed with brain tumours were excluded from the study.

METHODS

Self-report questionnaires, as well as standardized psychological test, were performed for the evaluation of psychosocial and cognitive functioning of the patients. Intellectual abilities were measured using the age-appropriate Wechsler intelligence scale (WISC-R, WAIS-R PL). Verbal (VIQ), performance (PIQ), and full scale intelligence quotients (FSIQ) were employed in analysis of cognitive function of the survivors group. Self-report questionnaires were administered to children and parents during their visit to the outpatient clinic. Both patients and parents were informed by mail about the planned examination and informed consent was obtained from them. Each child and participating parent received separate questionnaires which they were expected to fill in independently and personally. The questionnaires items were related to the selected psychosocial functioning domains. The children were asked to state their scholastic competence, peer acceptance, physical well-being, future expectations, and parent's attitudes on a 3-point ("never", "sometimes", "often") or 2-point ("Yes" or "No") datasheet.

In our study, questionnaires were completed only by one parent of the cancer survivors. Mothers represented 65.4% of parents' group. More than 55% of mothers had a

secondary education level, while 40.7% had basic education. In the fathers' group, 20% of respondents achieved secondary and 64% basic education level. Four percent of fathers completed high school.

Patients' and their parents' questionnaires (N=29, per each group) were analysed concurrently.

RESULTS

Cognitive functioning. The average FSIQ in the whole group of childhood cancer survivors living in rural areas was accounted for 108.2 with range from 65 to 133. In one third of patients (30.8%) a high level of intellectual functioning (FSIQ>120) was stated. More than 50% of survivors had an average level of intellectual development. Only 11.5% of studied children showed FSIQ below 80 points, and required additional support during schooling. The average verbal IQ (VIQ) approximated 81.7 with range 63-126. Within VIQ, 15.4% of children had a high developmental level (>120), and 15.4% of survivors represented a low developmental level (<80). The average level of performance IQ (PIQ) was 103.4 with range 64-141. Only 11.5% survivors had great difficulties with performance tasks and more than 30% of them revealed high abilities in these parameters.

Scholastic competence. From all studied survivors, 89.7% were still attending school. Only 2 boys completed their education at the basic level, and one child was just before starting his schooling. Almost 70% of survivors did not sustain learning difficulties. Less than 10% of the children had elicited specific intellectual deficits such as dyslexia, dysgraphia, decline of memory and concentration, or math disabilities, but their scholastic achievements were sustained as gratifying. However, almost 18% of the studied children experienced major learning difficulties.

One third of cancer survivors (27.6%) from rural areas claimed that they experienced more difficulties than their healthy peers. Different kinds of learning difficulties in the survived children was also stated by 33.3% of parents.

Peer acceptance. Almost 70% (67.9%) studied children never felt less healthy than their peers. A small group of survivors (10.5%) often experienced the sense of being inferior in comparison with peers. Only 7.1% of childhood cancer survivors claimed that they did not have any friendship with their peers. Also, 7.4% of parents stated that their children stayed away from school.

Physical wellbeing. One-fourth of survivors often visited an outpatient clinic, but 69% of children were medically examined only rarely. Visible changes in physical appearance were affirmed by 14.3% of childhood cancer survivors. Nevertheless, almost the whole group of children (96.5%) had a sense of good health and well-being. At the same time, 48% of parents noted late-effects of cancer

treatment in their children. However, the remaining parents did not state any problem with their child's health.

Generally, most survivors (67.9%) had no concealed history of their illness, and 42.9% of them were able to talk about it. Only 18.5% of parents preferred not to discuss the past threatening period in their child's life.

Nearly 35% of survived children claimed they had no school absences caused by malaise. Half of the studied group of survivors sometimes left classes because of malaise.

Future expectations. More than half of the survivors (60.7%) believed that they would accomplish some achievements in the future. Almost 40% of childhood cancer survivors never worried about their future, but 50% of them sometimes showed a tendency to upset themselves.

Parents attitudes. Three-thirds of parents decided to inform their sick child about the cancer diagnosis, and the same percentage of parents had faked some disease-related information to their healthy children. Thirty percent of parents reported some parenting troubles with their survived children. Mostly, they observed short-tempered behaviours and fluctuating emotions in their children. In comparison, only 11.1% of healthy siblings presented similar hardships.

Only 36% of parents acknowledged they often made demands on their children. Most of them, however, never (24% of them) or (40%) were rarely challenging. On the other hand, only 17.4% of children regarded their parents as frequently challenging. The remaining survivors noted their parents as never (43.5% of children) or rarely (39.1%) challenging. Only 10% of children regarded themselves as often handled preferentially by the parents. Most of the survived children also stated that they were treated preferentially and with a soft touch by teachers.

DISCUSSION

We have learned that childhood cancer treatment may affect a survivor's health many years later [3, 6, 8, 9]. Late effects can include organ system damage, alterations in growth and development, fertility problems, cognitive impairment, and quality of life issues. Survivors are also subjects at risk for second malignancies. Therefore, childhood cancer survivors require highly specialized aftercare and monitoring for late effects. In addition, adverse effects are not limited to physical and functional problems. There is growing appreciation of the role that socio-cultural and behavioural factors may play in cancer patient outcomes.

Research studies show that many survivors and their families experience significant psychosocial difficulties: fear of recurrence, sense of isolation, anxiety and depression; employment and insurance discrimination; altered body image; and relationship difficulties [8, 9]. Especially, individuals from lower educational backgrounds and low

income families are less likely to become "true-healthy" after cancer treatment [10, 13]. Sometimes, for those who have completed treatment, being disease free does not necessarily mean exactly that. Chronic illness persists over time, requires ongoing management, and involves major lifestyle changes and adaptations in one's environment. Most recommendations for treatment and aftercare psychosocial management are difficult sometimes in rural areas because of access barriers. Living in a rural area, experiencing side-effects such as cognitive impairments, low scholastic achievements, visible changes in the appearance, general malaise, any future expectations, isolation from peers, improper parents and social attitudes, are predictive of a significantly lower quality of life. Few studies have been conducted among those who are poor, elderly, low educated, as well as those who are living in rural areas, or come from ethnically diverse backgrounds [1, 2, 13, 24, 25, 31]. Also, findings from the largest cohort of childhood cancer survivors (over 16,000 survivors diagnosed before the age of 18, and ranging in age from 14 to 52 at time of study), have led the authors to theorize that psychosocial distress results from limited educational and employment opportunities that are secondary to late effects of chemotherapy and cancer-related social disruptions at critical developmental life stages [33].

Most of the studied cancer survivors living in rural areas did not reveal difficulties with cognitive and psychosocial functioning. Within cognitive functioning, more than half of the survivors presented an average level of intellectual development. The majority of evaluations of cognitive outcomes in children treated with cancer showed declines in the intellectual development level [17, 21, 29]. A retrospective study of survivors (except brain tumours), however demonstrated, that survivors were mostly able to compensate and adapt to overcome some cognitive problems [4, 7].

We observed a large disproportion between average verbal and performance intelligence quotients (81.7 points in VIQ vs. 103.4 points in PIQ). It may suggest that more difficulties in verbal tasks exist in studied survived children from rural areas. Children after cancer therapy can reveal deficits in such abilities as learning new material and performance in mathematics, reading, and spelling [17]. All the aforementioned abilities represent verbal intelligence. Generally, however, an average verbal intelligence quotient for cancer children study groups is higher than in our sample. In our previous published study, we also stated a lower average verbal IQ in childhood cancer survivors of less educated parents [27].

When verbal and performance abilities were analyzed separately, we found that 15.4% of children had intensive verbal impairments and 11.5% of survivors had great performance tasks difficulties. For these reasons, almost 18% of the studied children had experienced major learning difficulties. But only one tenth of studied children were diagnosed with a decline in the intellectual development

level, and required additional support during schooling or downgrading of the educational requirements. The study conducted in the Netherlands found that 7 out of 28 (25%) children treated for ALL with chemotherapy and radiation and assessed 10 years later had received special education services; this rate is much higher than for their siblings (4%). There were no differences in special education placements between children treated with chemotherapy without radiation and their siblings; however, they had significant deficits in auditory memory and fine-motor functioning [12]. This may indicate that additional supporting services in rural areas of our region are rather poor.

School absence continues to be a problem, even after a child completes therapy. Cancer survivors were also at higher risk of missing school for long periods and repeating a year of school [8]. In our study, half of the studied group of survivors sometimes left classes because of malaise. Nearly 35% of the remaining children claimed they had no school absences caused by malaise.

Learning disabilities are defined in terms of recognized discrepancies between intellectual functioning and academic achievement. A discrepancy may not be observed shortly following treatment, but may become evident at a later time. Because the types of impairments experienced by children with cancer emerge over time, neurocognitive evaluations need to be conducted on a schedule that anticipates areas of deficit [11, 16]. The educational outcomes in the studied group of children should be continued.

One third of cancer survivors from rural areas claimed that they experienced more difficulties than their healthy peers. Almost 70% of studied children never felt lesser than healthy peers. A small group of survivors (10.5%) often experienced a sense of being inferior in comparison with peers. In the study by Kazak *et al.* most survivors reported feeling different from their peers, although two-thirds felt the differences were more positive than negative. On the other hand, the survivors had fewer general health worries than their peers [14]. Studies of adult survivors of childhood cancer have shown poor functioning in the areas of friendships and social contacts [15].

Visible changes in physical appearance were affirmed by 14.3% of childhood cancer survivors. Nevertheless, almost the whole group of children (96.5%) had a sense of good health and well-being. Self-reported health status was more often negative in survivors than in peers, and survivors had more worries about late effects such as second cancers and fertility issues [14].

More than half of the survivors (60.7%) believed that they would accomplish some achievements in the future. Almost 40% of childhood cancer survivors never worried about their future, and a further 50% sometimes showed a tendency to upset themselves. Several studies have found that one of the strongest predictors of survivors' adjustment and life expectations was maternal coping. Also, Overbaugh *et al.* showed a strong relationship between parents' future life expectations and adolescents' self-esteem [22].

In our study, most parents never (24% of them) or rarely (40%) were challenging. And only 17.4% of children regarded their parents as frequently challenging. This may suggest that most survivors are unnecessarily protected against everyday life competition.

In our study, childhood cancer survivors living in rural areas represented 42% of all after-cared patients who were diagnosed between 1993-1995 and fulfilled established study inclusion criteria. We did not observe any significant differences in global cognitive functioning of cancer survivors from urban-rural areas. But the findings with respect to the other dimensions of psychosocial adjustment were inconsistent and unreliable. This might be attributed to limitations of the study designs, small sample size and lack of control groups. Lack of standardized instruments for quality of life estimation also limited this study.

In conclusion, children living in rural areas achieve normal levels of psychological and social functioning, and their families adapt well. All survivors, however, even those apparently doing quite well, experience at least occasional problems in social adjustment and continue to be concerned about their medical and social futures. There is a small but significant minority of survivors who remain seriously troubled and are impaired by their psychological problems [32, 34]. The group of seriously troubled cancer survivors from rural areas are more under privileged than their urban counterparts in access to additional supporting services.

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