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Network Oncology Specialist Advisory Service – A Survey of the Psychosocial Situation of Long Term Cancer Survivors During Childhood or Adolescents

Netzwerk für Onkologische Fachberatung – Fragebogenstudie zur Psychosozialen Situation von Survivoren einer Krebserkrankung im Kindes- oder Jugendalter

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Key words

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ABSTRACT

Background The number of long term cancer survivors during childhood or adolescence is increasing steadily. Survivors often

suffer from physical or psychosocial long term effects. There is currently little data on the arrangement of long term aftercare in the field of psychosocial care.

Methods In November 2017 a questionnaire was sent to 1900 cancer survivors aged between 18 and 35 years whose diagnosis dated at least five years prior. The obtained data serve as a condition and needs assessment, how the (psychosocial) long-term aftercare is perceived by the survivors and what else is desired. The analysis was conducted using descriptive statistics as well as the calculation of bivariate correlations.

Results The response rate was 54.9% (n = 1.043). The median interval from the first diagnosis was 20 years. In total 666 survivors (63.9%) stated that they suffered from at least one long term effect. Within this, especially neurocognitive themes played a role. 87.2% of the respondents had the feeling that they had overcome the illness/therapy well.

Conclusion Through a stronger patient-focussed orientation concerning the current care and advisory services, the situation of long term survivors could be improved. This especially includes access to relevant information that focuses on the available psychosocial and welfare services, as well as to advisory and care services. Additionally, the development and expansion of care structures in the areas of neurocognition and psychotherapy is important to ensure long term participation attendance.

ZUSAMMENFASSUNG

Hintergrund Die Zahl der Langzeitüberlebenden nach einer Krebserkrankung im Kindes- oder Jugendalter (Survivor) steigt stetig. Survivor leiden nicht selten unter körperlichen oder psychosozialen Spätfolgen. Für die Gestaltung der Langzeitnachsorge im Bereich der psychosozialen Versorgung liegen bislang kaum Daten vor.

Methode 11/2017 wurde deutschlandweit ein Fragebogen an 1.900 Survivor im Alter von 18 bis 35 Jahren versandt, deren Erstdiagnose zum Befragungszeitpunkt mindestens fünf Jahre zurücklag. Die erhobenen Daten dienen als Zustands- und Bedarfserhebung, wie die (psychosozialen) Langzeitnachsorge von den Survivoren wahrgenommen und was darüber hinaus

gewünscht wird. Die Auswertung erfolgte mittels deskriptiver Statistik sowie der Berechnung bivariater Korrelationen.

Ergebnisse Der Rücklauf betrug 54,9 % (n = 1.043). Der mediane Abstand zur Erst-Diagnose betrug 20 Jahre. Insgesamt gaben 666 Survivor (63,9 %) an, mindestens eines der abgefragten Items/Symptome bei sich zu beobachten. Hierbei spielen besonders neurokognitive Themen eine Rolle. Viele Angebote der Langzeitnachsorge sind den Survivoren nicht bekannt. 87,2 % der Befragten haben das Gefühl, die Erkrankung/Therapie gut gemeistert zu haben.

Schlussfolgerung Eine stärkere patientenorientierte Ausrichtung der derzeitigen Versorgungs- und Beratungsangebote könnte die Situation von Langzeitüberlebenden noch verbessern. Zentral sind hierbei der Zugang zu gezielten Informationen, eine psychosoziale und sozialrechtliche Betreuung sowie der Zugang zu Beratungs- und Versorgungsangeboten. Auch der Auf- und Ausbau von Versorgungsstrukturen im Bereich der Neurokognition und Psychotherapie ist für die langfristige Sicherstellung von Partizipation wünschenswert.

Background

Around 2.100 children and adolescents are diagnosed with a haemato-oncological disease in Germany every year [5]. Among the most common are leukemias (29.7 %), tumors of the central nervous system (CNS, 23.6 %) and lymphomas (15.3 %) [5]. Due to significantly more differentiated diagnostics and multimodal therapy concepts in hemato-oncological treatment, the five-year survival rate has risen from 67 % in the early 1980s to 85 % at present [5]. Therefore, the number of long-term cancer survivors in childhood or adolescence (“survivors”) is steadily increasing. According to the German Childhood Cancer Register (DKKR), there are currently over 38.000 former patients in long-term follow-up care [5], the majority of whom are now 18 years or older [12].

Long-term effects of the disease and therapies are increasingly put into focus [12]. These can occur many years after the end of intensive treatment [23] with about more than two thirds of survivors suffering from those [1, 18]. The spectrum of potential long-term effects is substantial and spans across almost all medical specialist disciplines. Therefore, attempts for integration of specialized care across the board are increasing. In addition to aftercare in outpatient clinics, specialized offers have been developed and expanded over recent years. Some clinics in Germany offer interdisciplinary aftercare consultation hours for children, adolescents, and young adults with a history of suffering from cancer. These so called ‘survivor consultation hours’ aim at formerly affected people whose cancer was successfully treated at least five years ago. Interdisciplinary follow-up teams offer regular examinations to identify and treat possible late effects at an early stage [14]. Some pediatric oncology centers also offer transition clinics for survivors. These aim for the best possible continuity of health care by targeted, planned transition from child-centeredness to adult-orientation [26]. Nevertheless, to this day, many survivors are discharged into routine care carried out by general practitioners after completing therapy [6]. To assist those patients is the central mission of the Network for Oncology Specialist Advisory Service (NOF) which offers survivors support in individual life planning.

In addition to physical long-term effects on the cardiovascular and musculoskeletal system [20, 25], psychosocial long-term consequences may also occur. Psychosocial health needs and treatment are therefore rightly prioritized [17]. Even if most survivors report little or no psychosocial long-term effects, a significant subgroup faces serious problems [1]. The most common psychosocial

long-term effects include illness-related anxieties, depression, post-traumatic stress disorders, difficulties in school/vocational training and work, reduced quality of life and difficulties in social adjustment [13, 22, 23, 25]. According to Nathan et al. medical and psychosocial follow-up care for survivors affected by psychosocial long-term effects is fragmented [17].

The VIVE project carried out a German baseline survey on the current living situation, state of health and quality of life of long-term survivors, who developed cancer before the age of 15. First results show that survivors indicated a lower quality of life compared to a control group. In comparison to the non-cancer population, long-term survivors also more often continue to live with their parents and/or are not married [11].

In standardized surveys, the survivor’s perspective on possible late effects of the disease and therapy, as well as the resulting design of long-term follow-up care, is hardly taken into account. [13]. In addition, knowledge remains scarce concerning the everyday challenges and needs of long-term survivors. Specialists often do not recognize the difficulties in everyday life that survivors themselves however rate as significant long-term consequences – especially concerning psychosocial aspects. Existing support most commonly is limited to target evidence-based medical therapy of physical symptoms [4].

Methods

In this study we aim to assess the condition and needs of long-term follow-up care from the survivor’s point of view. In addition, more precise information was sought about aspects of (psychosocial) long-term follow-up care that could be optimized.

In 11/2017, 1.900 survivors across Germany who suffered from a hemato-oncological disease in childhood (0–15 years) and were between 18 and 35 years old at the time of the survey received a questionnaire including an explanatory cover letter via letter from the DKKR. Survivors returned completed questionnaires to the DKKR which then sent those to the NOF. We also included a leaflet with contact details for the NOF – for patients’ questions on the study or their own (long-term) follow-up care. To qualify for participation, the diagnosis of the survivor needed to be at least five years old at the time of survey. Relapse of disease or a palliative situation served as exclusion criteria. Survivors were selected by the DKKR to ensure representativity of the clinical landscape.

We used a questionnaire, designed based on results of 25 guideline-based interviews with survivors conducted across Germany (12/2014–08/2015), from which relevant topics relating to long-term follow-up care were identified [13]. Five survivors pre-tested the thusly developed questionnaire using a think-aloud method for comprehensibility of content.

Additionally, we assessed socio-demographic data, disease-specific characteristics (diagnosis, age, therapies), possible areas of long-term consequences, living situation as well as use of support and counseling services in long-term follow-up care.

Data were evaluated by means of descriptive statistics and the calculation of bivariate correlations to the above-mentioned areas using the analysis software SPSS Version 25.

A non-responder analysis, based on a Chi-square test (χ^2), was used to examine whether the participating survivors differed from non-participating survivors considering different parameters including age, gender, and the time since diagnosis. The study was approved by the ethics committee of Hannover Medical School, Germany (No. 2419–2014).

Results

Cohort Description

From a total of 1.900 survivors contacted, 1.043 completed a questionnaire and could be included in the study (response rate 54.9%). Of the respondents, 51.4% were female and 48.6% male. The respondents' age ranged between 18 and 35 years (inclusion criterion), the initial cancer diagnosis was on average 20 years ago. The non-responder analysis showed that female (χ^2 (df = 1) = 17.61; $p < 0.001$) and older people (> 30 years) (χ^2 (df = 3) = 18.37; $p < 0.001$) as well as persons whose diagnosis was made at least 15 or more years ago (χ^2 (df = 6) = 16.35; $p < 0.05$), participated significantly more often in the study. The age at first diagnosis was between 0 and 5 years in 38.3% and between 6 and 14 years old in 61.8% of the respondents. The most common underlying diagnoses were leukemias (35.3%) and brain/CNS tumors (25%). More than three quarters of the respondents (76.2%) received chemotherapy, more than half had one (or more) surgery performed (54.8%) and 43% had received radiation therapy (multiple answers possible). *Information from the survivors about which organ or which body region was irradiated is not available.*

The majority of survivors had no own children at the time of the survey (79.8%), approximately half of them were single (49.6%); 42.1% reported a university entrance qualification as their highest level of education, 40.8% of the respondents stated an apprenticeship or vocational school as their highest professional qualification. A quarter of the participants had a university degree (25.9%). 52.7% of survivors had a full-time job and 68.7% did not hold a (severely) disabled pass at the time of the survey.

Long-term effects

Long-term physical and neurocognitive long-term effects

666 survivors (63.9%) stated suffering from challenges and symptoms that they attributed as late effects of disease and/or therapy. Of those 666 survivors, 43.6% reported long-term effects in one or two areas, 51.6% were affected in at least three areas, and only

4.8% reported no long-term effects. According to participants' responses, 76.6 and 80.0% of survivors from brain/CNS and bone tumor, respectively, suffered from long-term effects of the disease/therapy. More than half of survivors from leukemia, soft tissue tumors, lymphoma, and germ cell tumors were affected by long-term effects.

Functions of neurocognition and sensory impressions were among the subjectively perceived long-term effects (see ► **Table 1**). Fatigue (33.8%), psychological long-term effects (32%), concentration problems (30.6%) and limitations in vision (26%) were stated most often. As part of the follow-up in these areas, 100 survivors (9.6%) received a neuropsychological test (e. g., for memory or attention span), while 689 affected persons (66.1%) received no such test. The remaining 24.3% could not remember a test being performed.

Psychosocial long-term effects

Of the survivors, 87.2% reported overall satisfaction with their life at the time of the survey; 85.0% lived openly with their illness in private settings and 60.2% in a professional context; 14% of the respondents depended on the support of others. Here, family structures played a major role: 19.4% of respondents stated daily chores were done on their behalf, 22.3% felt that their families were overprotecting. Survivors, who received support for everyday tasks from their families, felt significantly more likely to be dependent on the support of others ($\rho = 0.40$, $p < 0.001$). ► **Figure 1** shows the influence of cancer on the further course of life from the point of view of those affected. Of note, 42.6% of survivors continued to feel a necessity for information about potential long-term effects of the disease/therapy. Furthermore, every fourth person wished for support in their professional life due to the illness and/or its consequences (22.1%) and concerning the meaning of life/quality of life (25.5%). 15.7% felt that they were overburdened by daily demands; these survivors were significantly more likely to report lower satisfaction with their current life ($\rho = -0.42$, $p < 0.001$). The fear of a disease relapse existed in 45.3% ($n = 472$) of all respondents.

Utilization of care and counseling offers in long-term follow-up care

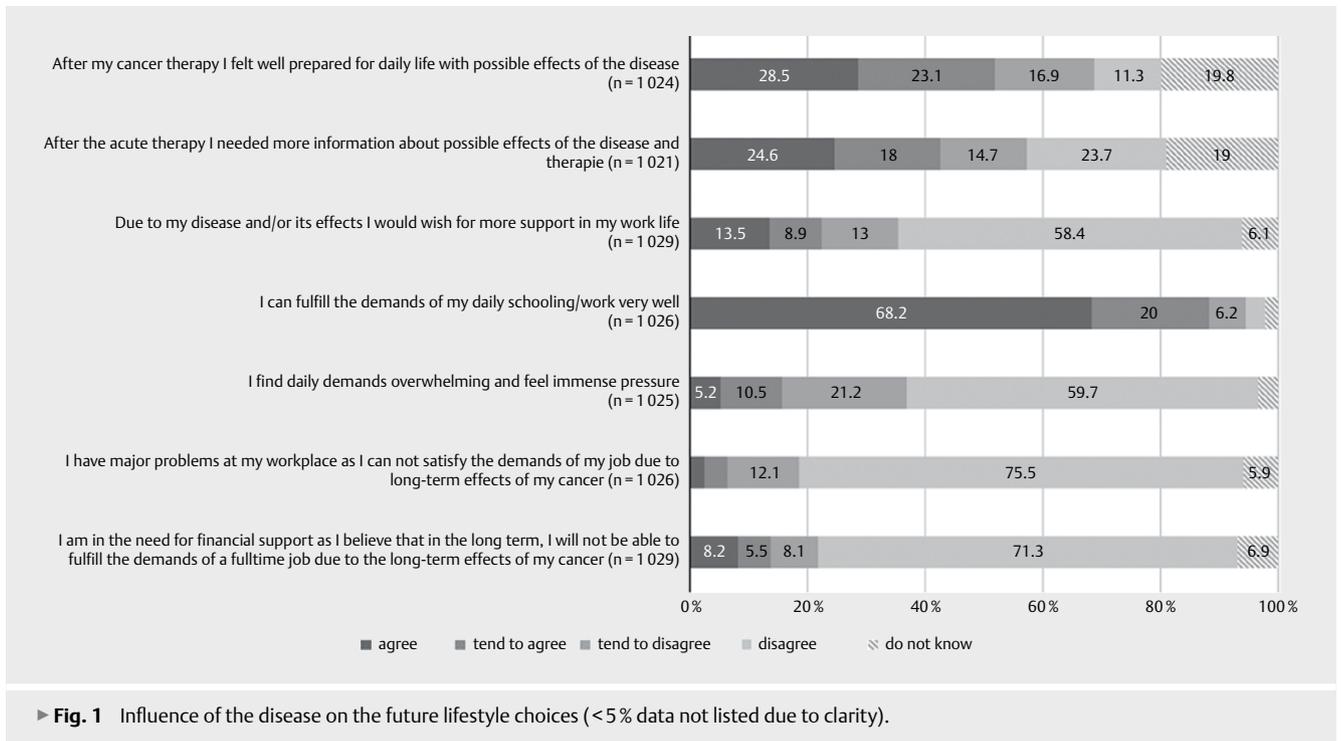
Care offers In long-term aftercare, 161 respondents (15.4%) made use of a follow-up consultation in a pediatric oncology clinic, 171 survivors (16.4%) in a (non-pediatric oncology) hospital. Of those survivors who received radiation therapy ($n = 449$), 7.8% used long-term follow-up care, 56.7% saw no need for it. A further 27.5% were not aware of such an offer; the time between the diagnosis and the survey was on average 19.7 years in this group ($SD = 6.33$).

Regarding transition, only 6.4% of respondents reported currently using consultation hours. 55.1% saw no need for transition consultation hours and almost a third (29.2%) were not aware of the offer in the first place. A similar picture emerged with the care provided by survivor consultations: half of the respondents (50.2%) did not feel the need for such an offer and 36.2% were not aware of this option. Only 4.8% made use of a survivor consultation. Survivors, who feared a relapse of the cancerous disease, used child oncological follow-up consultation hours significantly more often (χ^2 (df = 1) = 6.00; $p = 0.0014$). They also used significantly more frequently follow-up consultation hours in a (non-child oncologi-

► **Table 1** Reported late-effects from the survivor's point of view - differentiated according to the most common therapy combinations.

Late effects (multiple answers)	Surgery/Chemo-/Radiation-Therapy* (n = 150)		Chemo-/Radiation-Therapy* (n = 98)		Surgery/Chemotherapy (n = 88)		Chemotherapy (n = 103)		Surgery (n = 89)		Total (n = 528)	
	n	%	n	%	n	%	n	%	n	%	n	%
Exhaustibility	66	44.0	28	28.6	23	26.1	25	24.3	29	32.6	171	32.4
Psyche	38	25.3	31	31.6	28	31.8	40	38.8	33	37.1	170	32.2
Concentration problems	62	41.3	27	27.6	16	18.2	28	27.2	22	24.7	155	29.4
See	45	30.0	21	21.4	12	13.6	13	12.6	36	40.4	127	24.1
Teeth	46	30.7	29	29.6	16	18.2	22	21.4	7	7.9	120	22.7
Hormones	45	30.0	25	25.5	11	12.5	14	13.6	18	20.2	113	21.4
Memory performance	50	33.3	19	19.4	7	8.0	14	13.6	19	21.3	109	20.6
Attention Span	40	26.7	20	20.4	6	6.8	21	20.4	15	16.9	102	19.3
Bone	39	26.0	15	15.3	21	23.9	20	19.4	6	6.7	101	19.1
Fertility	36	24.0	25	25.5	13	14.8	15	14.6	12	13.5	101	19.1
Hear	43	28.7	11	11.2	20	22.7	2	1.9	9	10.1	85	16.1
Sensory disturbances	35	23.3	11	11.2	14	15.9	7	6.8	15	16.9	82	15.5
Skin	27	18.0	16	16.3	11	12.5	18	17.5	8	9.0	80	15.2
Word finding disorders	32	21.3	11	11.2	4	4.5	13	12.6	13	14.6	73	13.8
Relapse	18	12.0	10	10.2	6	6.8	2	1.9	10	11.2	46	8.7
Heart	12	8.0	12	12.2	8	9.1	5	4.9	1	1.1	38	7.2
Excretions	16	10.7	6	6.1	6	6.8	3	2.9	3	3.4	34	6.4
Second cancer	10	6.7	7	7.1	4	4.5	-	0	4	4.5	25	4.7
Diagnosis	n	%	n	%	n	%	n	%	n	%	n	%
Leukemia	9	6.0	65	66.3	8	9.1	78	75.7	-	0	160	30.3
Brain-/CNS Tumor	77	51.3	8	8.2	7	8.0	2	1.9	62	69.7	156	29.5
Lymphoma	10	6.7	15	15.3	8	9.1	15	14.6	-	0	48	9.1
Bone tumor	11	7.3	1	1.0	26	29.5	-	0	-	0	38	7.2
Soft tissue tumors	15	10.0	4	4.1	9	10.2	1	1.0	1	1.1	30	5.7
Others	28	18.7	5	5.1	30	34.0	7	6.8	26	29.2	96	18.2
Total	150	100%	98	100%	88	100%	103	100%	89	100%	528	100%

* Note: There is no information available from the survivor about which organ or which body region was irradiated.



cal) hospital (χ^2 (df = 1) = 17.43; $p < 0.001$), transition consultation hours (χ^2 (df = 1) = 4.23; $p = 0.040$), survivor consultation hours (χ^2 (df = 1) = 13.06; $p < 0.001$) or aftercare through radiation therapy (χ^2 (df = 1) = 5.67; $p = 0.017$) more often compared with survivors without fear of relapse.

Counseling services The counseling service used most frequently in long-term follow-up was advice on current follow-up recommendations (23.9%), whereby half of the survivors (47%) stated no need in this area. In contrast, advisory services on compensation for disadvantages (25.9%), pension insurance (25.6%) and current follow-up recommendations (24.1%) were not known to every fourth respondent. Of all respondents, 17.1% received psychotherapy or were currently receiving psychotherapeutic treatment. At the time of the survey or earlier, 27.9% of respondents stated a need for psychotherapy to better cope with illness. Those survivors with a need for psychotherapy used significantly more follow-up consultation hours in a (non-pediatric oncology) hospital (χ^2 (df = 1) = 4.43; $p = 0.035$), transition consultation hours (χ^2 (df = 1) = 5.77; $p = 0.016$) or follow-up care through radiation therapy (χ^2 (df = 1) = 16.62; $p < 0.001$) compared with survivors without the need for psychotherapeutic support.

Information gathering

39.5% of respondents named self-research or the Internet as sources of information on disease-specific aftercare, 30.5% turned to specialist staff for this. Exchange with other long-term survivors (4.2%) or in self-help groups (1.8%) were rarely used. 29.3% of survivors did not need any information concerning this topic.

Requests for the design of (long-term) aftercare

During the survey, information could be given on topics in which survivors required additional support or did not feel adequately in-

formed. Multiple answers were possible. A thematic sorting resulted in six main areas (see ► **Table 2**) but does not represent an all-encompassing overview. The most frequently mentioned topics regarding information and support needs were:

- 1) fertility/desire for children,
- 2) long-term consequences,
- 3) aspects of social law,
- 4) long-term aftercare,
- 5) contact persons and
- 6) psychological aspects.

For example, survivors required information on insurance options, advice on compensation for disadvantages in vocational training/studies and support in processing social benefits claims. The need for information on dealing with the inability to carry out certain jobs following the (former) illness were also mentioned. In the area of long-term follow-up care, survivors requested follow-up plans with fixed time intervals, reminders of preventive examinations and long-term contact persons. There was also a need for basic information on the definition and design of long-term follow-up care.

Discussion

For years, (inter-) national studies focused on determining the occurrence of long-term effects and deriving appropriate recommendations. According to Signorelli et al., survivors who regularly visit a follow-up clinic as part of long-term follow-up care show earlier detection of late effects and a reduced number of hospital stays compared to survivors who did not visit follow-up clinics [7, 24]. In addition, survivors who are regularly treated in long-term follow-up care have better knowledge of possible long-term effects and treatment and higher health-related self-efficacy. [15, 16]. So far, there

► **Table 2** Survivors' requests for information and support in (long-term) follow-up care - overview of the most frequently listed areas with examples.

Fertility/Desire for children	Request for information and support from the survivors
Fertility	– Influence of the disease and therapy on fertility
Inheritance of the disease	– Effects and consequences of the disease and therapy on one's own children
Late effects	Requests for information and support from the survivors
What kind of long-term effects can occur?	– Education about possible late effects and delimitation from other problems
Late effects from therapy(s)	– Education about late effects of radiation therapy/chemotherapy
Relapse	– Information and consultation hours on the risk of recurrence
Dealing with late effects	– Information on how late effects can be accepted and how everyday life can be structured with them
Social law aspects	Requests for information and support from the survivors
Insurance	– Support in communication with insurance companies – Information about the conclusion/exclusion of certain insurances due to the illness (e.g. occupational disability insurance, although one is considered "cured")
Advice on existing claims	– Advice and information on entitlements, e.g. in relation to pensions, severe disabilities and financial aid – Support in the implementation of social law claims
School, training, studies, and work	– Support options in training/studies – Advice and information on claims for compensation for disadvantages and support in the workplace – Information on jobs that can no longer be taken due to the illness
Long-term follow up care	Requests for information and support from the survivors
Information's	– Information about what long-term follow-up-care includes and how it should be designed – Long-term follow-up plan with fixed time intervals (checklist) & reminders for preventive examinations
Specialized medical care	– Information and advice on targeted follow-up consultations – Contact persons for long-term follow-up care
Enlightenment	– Desire for advice and information on the illness at the time and the course of therapy
Information on current studies	– Advice on new research results and new treatment methods
Contact persons	Requests for information and support from the survivors
General contact points	– Desire for general contact points in the field of long-term follow-up, to get questions answered and to be able to plan the follow-up individually
Other survivors	– Contact/exchange with other survivors even after completion of therapy
Psychological aspects	Requests for information and support from the survivors
Psychological counseling	– Psychological follow-up care – Psychological support in coping with illness – Psychological support for siblings
Suitable therapists	– Support in the search for suitable therapists – Missing contact persons in this area

is no nationwide comprehensive offer of specialized care for adult survivors of childhood and adolescent cancer in Germany. [7].

Long-term effects in sensory impressions and neurocognition as well as psychological care

The current support landscape in Germany hardly provides any offers in the field of neurocognition or sensory impressions. However, impairments in these areas have been recognized to have a massive impact on opportunities for social participation [19]. Missing or inadequate diagnostics may influence the patients' entire further life as well as general development [10]. This is particularly evident in the context of education and professional success. For survivors, however, there seems to be a lack of access to specialized diagnostics – so far, only 9.6% of our respondents received a neuropsychological test.

Our data are self-reported by survivors, showing their subjectively perceived limitations in neurocognition and sensory impressions which they attribute to the disease and therapy. General con-

clusions about effects cannot be made due to the study design used.

As part of a targeted improvement in (long-term) follow-up care, standardized criteria for identifying those affected should be established and comprehensive neurocognitive testing and training courses be expanded. This could enable everyday diagnostics and participation-oriented therapy planning, ensure long-term participation of those affected and close the perceived gap in care.

About one third of the survivors stated that they were affected by psychological challenges and mentioned a need for psychological support, half suffered from fear of recurrence. Wenniger et al. showed in a survey in 2013 that 14% of survivors suffered from post-traumatic stress disorder due to the oncological disease and therapy [27]. According to data derived from the general population, around 27% of adults in Germany are affected by mental disorders each year, with anxiety disorders being the most common among those (15.3%). Depending on the diagnosed mental disorder, between 32% and 74% of the general population report the

use of health services [9]. This compares to 17.1 % of respondents in the study that made use of such services. Clearly, the comparability of these data is limited due to methodological differences. What both groups seem to have in common is a challenge to access appropriate psychotherapeutic support. With the reform of the German psychotherapy guidelines, this situation has improved: general waiting time for an initial appointment with a psychotherapist has been reduced from 12.5 to 5.7 weeks [3]. According to Kreimeike et al. survivor's report, however, they often do not - or only after long waiting times - receive professional therapeutic help, since not every psychotherapist feels able to care for former pediatric oncology patients [13]. We therefore propose an improvement in the range of professional psychological/psychotherapeutic care for survivors as well as the use of targeted screening instruments and contact points.

Obtaining information and making use of care and counseling offers in long-term follow-up care

A closer look at the results shows that there is a need for adjustment of construction and expansion as well as the design of specialized care and advisory services: on the one hand, over half of the respondents deemed the offer of transition and survivor consultation hours as not needed and consequently did not use it. On the other hand, a third of survivors were not even aware of such offers. Due to a lack of awareness, almost every fourth survivor reportedly did not use advice on follow-up care recommendations, compensation for disadvantages and pension insurance. Yet, here, too exists the expressed desire for such offers (see ► **Table 2**). This raises the questions of a) whether design of existing and planned offers adequately serves the needs of survivors, b) if the current focus of advice is appropriate, and c) whether survivors know that their psychosocial questions may also be addressed holistically in specialized contact points?

Central questions remain: How can knowledge be transferred to survivors via existing and novel offers in long-term follow-up care? One solution might be the establishment of central, mediating contact points that take on a higher-level pilot function. Connecting existing offers and bundling them centrally enables the referral of those affected to appropriate counseling and supply centers. These contact points might also serve in forwarding necessary and technically correct information on disease-specific (long-term) follow-up care. To the present time, information research is mostly done employing the Internet, as was reported by the respondents of our survey. Individual Internet search challenges survivors with the complexity of the information and the necessity to put it into the correct context. Both, the choice of the Internet as a source of information as well as its quality may also be a starting point for further research.

Given there is well-structured care in the acute- and aftercare phase, this raises the question of why a structured transfer of information and the establishment of standardized information procurement is not as successful for long-term follow-up care although information is available through multicenter study groups such as the Late-Effects Surveillance System Study [8].

A surprising result of our study is that about one third of respondents did not want any information on long-term follow-up care. It is conceivable that today's adult survivors no longer want

to deal with cancer in their childhood and adolescence [7] and therefore do not search for long-term follow-up care and possible long-term consequences. Another reason might be that formerly affected patients lose access to relevant offers due to their current status as a cured patient. According to Gebauer et al. many of those affected lack suitable contact persons in the transition from pediatric to general practitioner associated care who have knowledge of possible long-term effects, preventive recommendations, and experience in dealing with this patient group [7]. Knowledge of long-term effects is essential to support survivors to take responsibility for their own health and to act self-effectively and self-sufficiently [15].

Finally, the inclusion of all specialist disciplines in long-term follow-up likewise appears to be not sufficient. In our study, only a small proportion of those previously affected reported receiving aftercare through radiation therapists. Various studies have already shown that late effects of radiation can occur in areas and at times different to therapy [21]. Here, the time interval of up to ten years seems particularly relevant. Improved access to long-term follow-up care through radiation therapy and a focus on cooperation with the registry for recording radiogenic long-term effects in children and adolescents (RiSK) appear as suitable solutions to address this problem in the future [2].

Conclusion

Overall, 87.2 % of the respondents felt that they have mastered the disease and therapy well. Based on these results, it can be assumed that the current care situation, especially in the acute and aftercare setting, is perceived as being appropriate. Nevertheless, the results of this study also demonstrate a significant space for improvement in long-term follow-up care with a focus on efficient information transfer. Long-term psychosocial aftercare and social support should be given greater consideration, as there is an obvious undersupply from the point of view of those affected. To better promote social participation of former cancer patients through childhood and adolescence and to enable them to lead a self-determined life in the long term, greater emphasis should be placed on the needs of survivors when designing future support offers. Sustainable financing models for such services may form the basis for an adequate implementation of those strategies.

Conflict of Interest

The authors declare that they have no conflict of interest.

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