

Childhood Cancer Survivors:

what are their needs and expectations?

A national survey

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VOKK: established in 1987 by and for families of children with cancer

Mission: to support children with cancer and their families through all stages (so incl survivors) and help improve their quality of life through:

- ✓ information
- ✓ support of children and families
- ✓ advocacy

www.vokk.nl

Background



Growing group of survivors with different needs

More late effect research

Establishment of DCOG LATER

DCOG LATER expects input from survivors

VOKK representative on the board of SKION LATER

Questions



What do survivors expect from VOKK in terms of

- support
- information
- advocacy

Do they want to be involved in late effect research?

If so, how?

Webbased questionnaire



115 respondents

70% female

30% male

59% 14-25 yrs

27% > 28 yrs (oldest 56 yrs, diagnosis 1967)

75% member of VOKK

Diagnosis and treatment



Diagnosis

- 31% ALL
- 18% bone tumor
- 17% brain tumor
- 34% other
- 15% relapse

Treatment

- 84% chemotherapy
- 55% surgery
- 41% radiotherapy
- 7% stem cell transplant

I'm a Survivor



64% prefers 'survivor' above 'ex-patient' or 'overlever'/'overlevende' (*Dutch for survivor*)

I'll always be a patient.

I don't want to have a name or label.

I'm just like everybody else.

Late effects



81% physical

54% psychological

53% social

31% other e.g. financial, insurance, housing etc.

- 2/3 of the ALL survivors has psychological effects
- the majority of ALL survivors has social effects
- 81% of the bone tumour has no social effects

Late effects



I have been bullied a lot and therefore have little self-confidence.

People don'tt want to see me anymore because I had cancer.

I fear that it will return and every little pain or bump causes panic.

Especially at this age, when everyone around me starts a family, I'm confronted with my past disease and the consequences.

It's not easy to accept that I now live a totally different life with various limitations.

Everything in life costs a lot of energy.

Burden of late effects



5% very heavy burden

15% heavy burden

42% burden, but manageable

15% little burden

12% very little burden

11% no burden at all

- 50% of the ALL survivors experience very little or no burden at all

Burden of late effects



Perhaps I don't want to see it as late effects.

I'm not sure if my problems are related to the cancer and the treatments.

You learn to live with the consequences.

Information



44% received sufficient information from their doctor

- 31% wants more information about physical effects
 - 30% wants more info on consequences for relationships and fertility
 - 26% wants more info on psychological effects
 - 18% wants more info on consequences for employment
 - 18% wants more info on insurances and mortgage
 - 8% wants no information at all
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- especially ALL and nefroblastoma survivors showed a great interest in receiving information on physical late effects.

Information



I haven't seen a doctor for 25 years.

My doctor doesn't inform me at all about late effects.

My doctor doesn't take my symptoms seriously.

Contact with other Survivors



53% important (19% very important)

In which form?

66% activities

62% digitally

48% informal meetings

38% informative meetings

24% group sessions

16% phone

Contact with other Survivors



Unfortunately, a lot of my 'companions' are not alive anymore. In the seventies and early eighties almost 80% did not survive. The group of 40+ survivors is therefore small. I don't feel the need for contact with younger survivors because they can't imagine what we 'the old survivors' have been through.

Survivors immediately understand each other.

I have never met another survivor.

Scores of various services



E-news on activities, meetings and news: 79% important

Informative meetings: 35% important, 14% very important (49%)

Activities: 26% important, 20% very important (46%)

Meetings: 25% important, 20 very important (45%)

- ALL and neuroblastoma survivors: more interest in informative events
- brain tumor survivors more informal activities and meetings and contact with other survivors

Other expectations



Provide experience-based advice

Strengthen the expert group / expert network for personal contact and advocacy

Conclusion



Continue current activities such as conferences, activities and (informal) meetings

Continued collaboration with DCOG LATER on information

Use of social media, e-news and website

Facilitate sharing of experiences

Continued collaboration with DCOG LATER on long term follow-up and research

Actions since the survey



Continuation of current activities like conferences, activities and (informal) meetings: conference last April

Continued collaboration with DCOG LATER on information: later.skion.nl

Use more social media, e-news and website: Twitter, Facebook

Facilitate sharing of experiences: closed Facebook-group

Continued collaboration with DCOG LATER on long term follow-up and research: skionlaterstudie.nl

International collaboration



ICCCPO Survivors Network (ICCSN)

SIOPe: ENCCA

ESCCL

Pancare

Etc.