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Late effects, long-term problems, and unmet needs of cancer survivors

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Background

Great efforts and impressive progresses are being made in tumor treatment. Research and care concerning long-term problems and late effects of cancer in disease survivors is, however, still insufficient.

Methods

The FiX study enrolled 2,508 patients across 15 different cancer entities around 2 years after diagnosis via an Epidemiological Cancer Registry in Germany, with the primary aim to assess pattern, severity, and impact of fatigue. A follow-up survey was conducted between 12/2020 and 04/2021. Using a list with 36 potential long-term problems or late effects, participants were asked how much these are/were a burden to them (no/ little / moderate / significant / extreme burden), and, in case of burden, how they rate the received support for this problem (good / moderate / poor).

Results

1,874 participants (76%) completed the follow-up survey at a median (Q1, Q3) of 4.2 (3.8, 4.8) years after cancer diagnosis. This population had a mean (SD) age of 65.8 (11.2) years, and 49% were female.

The most frequently reported problems rated with at least moderate burden were: loss of physical capacity (40.7%), fatigue (38.5%), sleep problems (36.6%), sexual problems (35.4%), arthralgia (33.4%), anxiety (33.2%), and neuropathy (28.9%). Cardiac disorders and osteoporosis burdened 15.6% and 11.9% of survivors, respectively. Extreme burden was most frequently rated for sexual problems (10.1%), mainly in men with prostate cancer. This was also the problem with the highest proportion of dissatisfaction with received support (44.7% of affected survivors rated support as poor). Support for fatigue was rated as poor by 37.7% and as good only by 29.5% of affected survivors. Support was also reported as poor for neuropathy (35.9%), cognitive problems (35.3%), weight gain (34.7%), or hot flashes/night sweats (33.7%). In contrast, support in case of pain was rated as good by a majority (51.3%). Determinants of the different burdens and of satisfaction with support have been identified.

Conclusions

A significant number of cancer survivor suffer from long-term effects. Our study identified several groups with open needs for improvements in supportive care.

Clinical trial identification

NCT03318224.

Legal entity responsible for the study

The authors.

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Disclosure

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