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Help-seeking behaviour and attitudes towards internet-administered psychological support among adolescent and young adults treated for cancer during childhood

Submission date
15/02/2021

Registration date
17/02/2021

Last Edited
07/02/2024

Recruitment status
Stopped

Overall study status
Stopped

Condition category
Mental and Behavioural Disorders

☒ Prospectively registered
☒ Protocol
☐ Statistical analysis plan
☐ Results
☐ Individual participant data
☐ Record updated in last year

Plain English summary of protocol
Background and study aims
Adolescent and young adult childhood cancer survivors are at an increased risk of experiencing psychological difficulties, such as low mood, depression, anxiety or stress. However, adolescent and young adult cancer survivors also experience difficulties accessing psychological support. E-mental health delivering psychological support online or via smartphone applications may help survivors access support.
At present, little is known about:
1. Help-seeking behaviour in adolescent and young adult childhood cancer survivors, for example, what might help survivors to access support, and what might stop survivors from accessing support.
2. The acceptability of e-mental health for adolescent and young adult cancer survivors.
Therefore, the researchers want to undertake an online and paper-based survey and interview study to find out:
1. What factors help, and what factors get in the way of help-seeking behaviour in adolescent and young adult childhood cancer survivors?
2. How acceptable is e-mental health for adolescent and young adult childhood cancer survivors?
3. What preferences do adolescent and young adult childhood cancer survivors have for support for psychological difficulties?

Who can participate?
Adolescents and young adults aged 16-39, who were diagnosed with cancer aged 0-18 and have completed successful cancer treatment

What does the study involve?
Participants will be asked to complete a short consent form, either online or via the post. Participants will then need to complete the online survey or complete the paper survey and

return in the post using the stamped addressed envelope. Completing the survey will take about 20 minutes. A subset of participants will also be invited to take part in an interview by secure video conferencing or over the telephone, which will take about 45 minutes.

What are the possible benefits and risks of participating?
People often report that taking part in research and sharing experiences is enjoyable and fun. Joining the study will hopefully help us to develop acceptable support for young cancer survivors in the future.
Taking part does take time. Some of the questions we ask in the survey are personal and people might find these subjects difficult to discuss.

Where is the study run from?
Uppsala University (Sweden)

When is the study starting and how long is it expected to run for?
January 2020 to May 2022

Who is funding the study?
Fredrik O Ingrid Thurings Stiftelse (Sweden)

Who is the main contact?
Joanne Woodford
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Contact information

Type(s)
Scientific

Contact name
Dr Joanne Woodford

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
DNR 2020-06271

Study information

Scientific Title
Help-seeking behaviour and attitudes towards internet-administered psychological support among adolescent and young adults previously treated for cancer during childhood: a survey and embedded qualitative interview study in Sweden

Acronym
FUNCA

Study objectives
1. Are there associations between predisposing, enabling, environmental, and needs related health service use factors, informed by Andersen's behavioural model of health, and help-seeking behaviour (actual help-seeking and type of help-seeking) within an adolescent or young adult childhood cancer survivor (AYACCS) population?
2. What attitudes are held by an AYACCS population towards e-mental health (MH) interventions?
3. What is the perceived need for mental health support within an AYACCS population?
4. What are AYACCS experiences of past receipt of cancer-specific and non-cancer experience specific mental health support?
5. What preferences do an AYACCS population hold towards mental health support related to their cancer experience?
6. What are the barriers and facilitators do an AYACCA population experience seeking help for mental health support related to their cancer experience?

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 17/12/2020, Swedish Ethical Review Authority (Etikprövningsmyndigheten, Box 2110, 750 02 Uppsala, Sweden; +46 (0)10 475 08 00; registrator@etikprovning.se), ref: 2020-06271

Study design
Online and paper-based cross-sectional self-report survey and embedded qualitative interview study

Primary study design
Observational

Study type(s)
Other

Health condition(s) or problem(s) studied

Interventions
A cross-sectional survey self-report survey and embedded qualitative interview study, with no longitudinal follow-up. The survey has 98 items in Swedish and comprises eight subsections: (1) sociodemographic characteristics (11 items); (2) clinical cancer-related characteristics (3 items); (3) actual help-seeking behaviour (2 items); (4) attitudes towards internet-administered interventions (17 items); (5) stigma of mental illness (5 items); (6) mental health literacy (26 items); (7) social support (12 items) and; (8) current symptoms of depression, anxiety, and stress (21 items). The survey is designed to be completed in approximately 20 minutes. Qualitative interviews will explore: (1) perceived need for mental health support; (2) past experience of receiving mental health support; (3) preferences for support; and (4) barriers and facilitators to help-seeking.

Intervention Type
Other

Primary outcome(s)
Measured at one timepoint within this cross-sectional survey:
1. Sociodemographic characteristics measured using a survey with questions developed by the study team at one timepoint
2. Clinical cancer-related characteristics measured using a survey with questions developed by the study team at one timepoint
3. Actual help-seeking behaviour measured using a survey with questions developed by the study team at one timepoint
4. Attitudes towards internet-administered interventions measured using the e-Therapy Attitudes Measure (ETAM) at one timepoint
5. Symptoms of depression, anxiety, and stress measured using the Depression Anxiety and Stress Scale (DASS-21) at one timepoint
6. Stigma of mental illness measured using the Stigma Scale for Receiving Psychological Help (SSRPH) at one timepoint
7. Social support measured using the Interpersonal Support Evaluation List (ISEL-12) at one timepoint
8. Mental health literacy measured using a multicomponent mental health literacy measure at one timepoint

Key secondary outcome(s))
There are no secondary outcome measures

Completion date
31/05/2022

Reason abandoned (if study stopped)
Lack of staff/facilities/resources

Eligibility

Key inclusion criteria

1. 16-39 years at study start
2. Diagnosed with cancer when 0-18 years
3. Completed successful cancer treatment (including relapses) at a minimum 3 months ago according to self-report
4. Able to read and write in Swedish
5. Currently reside in Sweden

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Mixed

Sex
All

Key exclusion criteria
Does not meet inclusion criteria

Date of first enrolment
01/05/2021

Date of final enrolment
01/10/2021

Locations

Countries of recruitment
Sweden

Study participating centre
Uppsala University
Clinical Psychology in Health Care
Department of Women's and Children's Health
MTC House
Dag Hammarskjölds väg 14B
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Sponsor information

Organisation
Uppsala University

ROR
https://ror.org/048a87296

Funder(s)

Funder type
Charity

Funder Name
Fredrik O Ingrid Thurings Stiftelse

Results and Publications

Individual participant data (IPD) sharing plan
As Uppsala University does not have a policy concerning Open Access research data, data will not be shared on an open data repository and rather requests for data should be made to Dr Joanne Woodford (joanne.woodford@kbh.uu.se). Under Swedish Archival Law, individual-level participant data is considered the same as personal data, and thus cannot be made open access. Upon reasonable request, aggregate quantitative data from the survey may be available. Specific extracts of individual-level participant data that protects both data integrity and individuals from being identified from the data may also be available upon reasonable request. For example, for the purposes of including within an individual participant data meta-analysis. Qualitative data from the semi-structured interviews will not be made available.

IPD sharing plan summary
Available on request

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Protocol article		01/04/2021	17/05/2021	Yes	No
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes