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ARTICLE

An inventory of psychosocial oncological interventions in The Netherlands: identifying availability, gaps, and overlap in care provision

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ABSTRACT

Purpose: While a wide range of psychosocial oncological (PO) interventions has been developed, a systematic overview of interventions to inform patients, care providers, as well as researchers, policy makers and health insurers, is lacking. The aims of this paper were (1) to describe the attainment of this overview, which may be used in other jurisdictions and for other health conditions and (2) to reflect on what determines developments in this field.

Methods: Dutch researchers and care providers were invited to describe PO-interventions they apply in research or clinical practice. Selection criteria for what constituted a PO-intervention were determined. The input was organized in 12 predefined categories (e.g. physical functioning, genetics).

Findings: Sixty-six PO-interventions were included in the overview. Two major categories were psychosocial functioning (24%) and physical functioning and recovery (24%). Interventions are mostly directed at adults (65%) and not aimed at a specific type of cancer (61%). Nearly 25% of the interventions lacked scientific underpinning.

Conclusions: This paper provides an overview of Dutch PO-interventions and input on what drives their development. The categorizing method can be used in other jurisdictions and for other health care conditions. A next step would be to investigate the effectiveness and evidence of PO-interventions.

Implications for Psychosocial Providers and Policy: The open access overview of interventions provides referral information for care providers. By identifying possible gaps and overlap, the overview looks at possible drivers behind developments in this field which will be of interest to policy makers.

KEYWORDS

needs assessment; health care utilization; cancer; psychosocial support systems psychosocial oncology; knowledge translation

Introduction

The large body of research into the psychosocial well-being of cancer patients and survivors has gone hand in hand with the development of many interventions to improve the situation of patients, survivors, and their significant others.^{1–9} These so-called psychosocial oncological (PO) interventions may range from interventions on cancer-related fatigue to interventions to support patients to return to work, or help both patients and health care providers in their shared decision making.^{10–12} Access to and knowledge about PO-interventions is crucial. Patients and their relatives should know which interventions are available on a national and regional level.¹³ Equally important is that health care professionals, policy makers, researchers and health care insurers can be informed about developments in this care domain. The mission of the Dutch Association for Psychosocial Oncology (NVPO) is to enable high quality, accessible and timely psychosocial care as an integral part of oncological care. As part of their mission, the NVPO developed a two-step Knowledge Translation (KT) Action Plan. The first step was to compose a yearly inventory of current Dutch *scientific research* in PO. Since 2013, this resulted in an open access online ‘Annual Research Index’ (ARI) (https://issuu.com/nvpo/docs/nvpo_jaarindex_2016?e=14606812/42178347, in Dutch). For the ARI, all PO-researchers in the Netherlands are asked every year to complete a structured template per scientific study they are conducting. Their contributions are grouped into 12 predefined categories and bundled in the online ARI. The use of the template ensures that information per study is presented in a comparable format. The ARI does not claim to offer a complete overview of all PO-research in the Netherlands; researchers themselves provide all information on a voluntary basis and are responsible for the content. Over the years, more and more researchers contribute to the ARI, which has become a well-used resource, not only for researchers but also for policy makers and grant providers.¹⁴ The second step in the KT Action Plan was to undertake an inventory of all *available interventions* in PO in the Netherlands, with a first focus on availability, not on effectiveness. For this inventory, a second template was developed. The NVPO acknowledged the importance of two-way traffic: not only interventions developed in scientific studies but also those with their roots in clinical practice should be considered.

An overview of PO-interventions falls within the remit of Knowledge Translation¹⁵, as it informs patients and health care providers, and it provides information for grant providers, researchers, and policy makers about developments in the field. Having an overview of available PO-interventions can contribute towards improved integration of PO-care.^{16,17} In addition, and of particular interest to researchers, policy makers, and

grant providers, the overview may help identify overdevelopment in certain PO research and care areas, as well as gaps in other areas. Also, enablers (e.g., scalability) and hurdles (e.g., lack of health insurance coverage) in the implementation process may come to the surface.

Cancer prevalence and cancer care research in the Netherlands are quite similar to many other Western countries, as are issues related to access to and implementation of PO-interventions in clinical practice, making this study relevant to a wider jurisdiction. Therefore, in this paper, we describe the process of attaining this overview of PO-interventions, and we reflect on how this overview informs implementation and developments in this field.

Methods

Intervention template and procedure

A structured template was developed by the authors to gather basic information regarding PO-interventions, such as the title of the intervention, the developers involved, and the funding body. Next, more detailed questions were asked on, for example, the target group, care providers involved, the type of cancer, and stage of the illness. Information on scientific evidence of the intervention, KT and implementation was also requested. All answers to the questions were restricted to a word limit. The results were to be summarized to a maximum of two pages per intervention.

A cover letter outlined that all interventions would be assessed against a set of predefined inclusion and exclusion criteria before inclusion in the inventory. The template and the cover letter were sent by email to all identified researchers and (clinical) experts, including all NVPO-members, hospitals (departments of medical psychology and medical social work) and institutions in the field of PO in the Netherlands. As a result, the questionnaire was sent to over a thousand different email addresses. Data collection ran from September 2014 to February 2015. Addressees were given 4 weeks to reply. One reminder was sent. By submitting the completed questionnaire, participants agreed to their results being published in an open access report.

Criteria for inclusion

There were no predetermined criteria available to identify and assess the interventions. PO-definitions appear to be predominantly *descriptive* rather than provide criteria for in- and exclusion. For example, Uitterhoeve et al. stated that: “psychosocial interventions are defined to include counselling/psychotherapy, behavior therapy, education, and provision of information,

social support or a combination of interventions”.¹⁸ For the purpose of this study, the authors defined an additional set of criteria for a PO-intervention. This was based both on a definition of PO-care and on a definition of what constitutes an intervention.^{19,20} The formulated seven criteria were sent for feedback to experts in the field, which did not lead to major adjustments. According to the authors and the experts, PO-interventions to be included in the overview had to be:

1. oncology-specific. For this first overview, only interventions explicitly developed for cancer patients or their carers were to be included as a suitable reflection of the breadth and also the specificity of the domain. This excluded, for this overview, interventions such as generic Cognitive Behavioral Therapy (CBT);
2. offered or developed by (basic) professional health care workers. This was to ensure professional delivery of care and quality of care, while not excluding self-management;
3. face-to-face, offered online or in a blended form, given the increasing development of e-health interventions;
4. focused on prevention of complaints or improvement of psychosocial well-being of cancer patients and survivors or their carers;
5. focused on psychosocial and/or on physical recovery;
6. clearly described, transferable and scalable. The emphasis was on interventions, available to larger groups of patients, and offered through multiple care providers or institutions. Interventions developed and used by a sole care provider and lacking a clear rationale, context and description were excluded;
7. developed or offered in the Netherlands. This does not exclude interventions that were originally developed in another jurisdiction.

Results

Intervention selection

In total, 98 submissions were received, 51 from researchers and 47 from care providers or care institutions. The authors independently assessed all submitted interventions on the basis of the seven criteria. Sixty-six (67%) submissions were included in the inventory. Thirty-two submissions (33%) were excluded because of the following reasons: (1) they did not comply with the sixth criterion, i.e., their description was not transparent enough, or they were too tied to a sole practitioner and lacked scalability (N = 10); (2) they were not a specific PO-intervention, but a description of general care provision, such as generic CBT or mindfulness training, not specifically developed for cancer-related care (N = 7); (3) their description in the

template was incomplete, even after follow-up ($N=4$); (4) they were local applications of one and the same program: 'Recovery and Balance'. This program was included only once ($N=3$); (5) they suggested having influence on the actual cancer, the illness process and the treatment ($N=2$). The NVPO, as an organization, does not condone claims of this nature. They are seen as harmful; (6) it was a research proposal and not an intervention ($N=1$); (7) the involvement of a qualified health care professional was not demonstrated ($N=1$); (8) it was professional development for health care workers and not aimed at patients ($N=1$); (9) it offered standard somatic care ($N=1$); (10) its focus was on organization of care and not on patients ($N=1$); (11) it was a standard mental health care intervention ($N=1$).

The resulting 66 interventions were categorized in the 12 predefined categories, identical to the ARI categories: 1) Psychosocial functioning, (2) Physical functioning and recovery, (3) Cognitive functioning, (4) Pediatric and adolescent oncology, (5) Significant others, (6) Prevention, screening/Quality of Life, (7) Communication and patient information, (8) Work and survivorship, (9) Intimacy and sexuality, (10) Palliative care and end of life care, (11) Meaning and spirituality, (12) Genetics. The main characteristics are summarized in [Tables 1–12](#), which formed the basis for the description of the results below.

The two largest groups of interventions were those related to the categories 'Psychosocial functioning' (16 interventions, 24%) and 'Physical functioning and recovery' (16 interventions, 24%). These 32 interventions covered almost 50% of the total number of interventions. This concentration is comparable to the results of the ARI, i.e., in these categories, the largest number of research projects was found.

Target group

Adults were the most prevalent target population (43 Interventions, 65%). They were followed by significant others (12, 18%), young adults (7, 11%) and children (5, 8%). One intervention focused on parents of a child with cancer. Twelve interventions (18%) did not provide information on the target population.

Type of cancer

Forty interventions (61%) did not specify a type of cancer. Of the remaining 26 interventions, 55% focused on the big five: skin cancer, breast cancer, colon cancer, lung cancer and prostate cancer, applying to the majority (66%) of patients in the Netherlands.²¹ The other remaining interventions

Table 1. Overview PO Interventions Category 1 - Psychosocial functioning.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
1	BeMind	MBCT for (breast) cancer patients as a large scale intervention for fear and depressive symptoms	Adults	Breast Cancer, Cancer in general	Anxiety, fear of relapse, depression, quality of life	Psychologist Social worker Psychiatrist	Face-to-face /online	5	Own institution and others	Research done / ongoing	Helen Dowling Institute and Radboud University Medical Centre
2	Dealing with breast cancer	To support women with breast cancer in their psychological recovery after treatment	Adults (women)	Breast Cancer	Fear of relapse, depressive symptoms, tension and relaxation, physical complaints	Social worker Nurse Other caretaker	Face-to-face	2	Own institution	Research done / ongoing	Integral Cancer Centre Netherlands and Home Care Drenthe
3	I-MBCT	Reduction of depressive symptoms by teaching patients other ways to deal with stressful situations	Adults	-	Depressive symptoms after treatment	Psychologist /Psychotherapist	Face-to-face	2	Own institution and others	Research done / ongoing	University Medical Centre Groningen
4	Problem Solve Training	Improve well-being through helping patients address stressful situations differently	Adults	-	-	Psychologist /Psychotherapist	Face-to-face	1,2	Own institution and others	Research done / ongoing	University Medical Centre Groningen
5	Resuming life after breast cancer	Online support for women who have been treated for breast cancer. Aim is to decrease complaints and increase resilience without professional help.	Adults (women)	Breast Cancer	Fatigue, fear of relapse, resuming work, intimacy	Self-help	Online	2	Own institution and others	Research done / ongoing	Radboud University Medical Centre
6	MBSR /MBCT	Group training to reduce fear and depression complaints and increase acceptance and quality of life.	-	-	Fearfulness, depressive symptoms, quality of life	Psychologist Social worker Psychiatrist Nurse	Face-to-face	1,2,3	Own institution and others	Research done / ongoing	Jon Kabat-Zinn, University of Massachusetts, USA (MBSR)
7	Learning to live with fear	Aims to teach patients with a high fear of recurrence to deal with their fear differently so as to reduce its presence in everyday life.	Adults	Breast Cancer Colorectal Cancer Prostate Cancer	Fear of relapse	Psychologist /Psychotherapist	Blended	2	Still being researched	Research done / ongoing	Radboud University Medical Centre

(continued)

Table 1. Continued.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
8	NUCAI	Help patients to deal with the physical, psychological and social consequences of head and neck cancer and its treatment.	Adults	Head and Neck Cancer	–	Nurse	Face-to-face	2	Own institution	Research done / ongoing	University Medical Centre Utrecht & Julius Centre
9	Distress / Colorectal Cancer	Early detection and if needed treatment of psychosocial distress following a stepped-care approach	Adults	Colorectal Cancer	Distress	Psychologist Nurse Psychiatrist	Blended	1	No	Research done / ongoing	VU University Medical Centre & GGZ Ingeest
10	Stepped Care Distress	Reduction of psychological distress.	Adults	Haematological Cancer	Distress	Physio	Blended	2	No	Research done / ongoing	VU University Medical Centre & GGZ Ingeest
11	Relaxation and Meditation (Ontspanning en Meditatie)	Course to learn to be mindful in the present amidst the chaos that cancer can cause.	–	–	Stress, fatigue, fearfulness, emotions	Psychologist Social worker Volunteer	Face-to-face	–	Own institution and others	No research	Toon Hermans Home & Amarant
12	Continuing after Cancer (Kanker en nu verder)	Group sessions to share experiences around the cancer process.	–	–	Dealing with emotions, fear of relapse	Psychologist Social worker Volunteer	Face-to-face	2	Own institution and others	No research	Toon Hermans Home & Amarant
13	Reduced Fear around Cancer (Minder angst bij kanker)	Online self-help tool to reduce fear of recurrence.	Adults	–	Fear of relapse	Psychologist / self-help	Online	2	Own institution	Research done / ongoing	Helen Dowling Institute
14	Therapeutic Weeks (Therapeutische weken)	Group treatment around emotional recuperation following cancer diagnosis and treatment.	Adults, Relatives	–	Cancer related issues	Psychologist Physio Other caretaker	Face-to-face	2,3	Own institution	No research	Les Vaux Foundation
15	Guidance with Loss of Health (Begeleiding gezondheids-verlies)	Support patients in their grieving process.	Adults, Relatives	–	–	Social worker	Blended	2	Own institution	No research	Netherlands Cancer Institute
16	Continuity Visits	Continuous support in an intensive period of bad news and on-going treatment.	Adults	–	–	Nurse	Face-to-face	1,2,3	Own institution and others	Research done / ongoing	ZorgSaam Zeeuws Vlaanderen.

t- General: (PO) Psychosocial Oncology, (–) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 2. Overview PO Interventions Category 2 - Physical functioning and recovery.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementa-tion	Research evidence	Provider / developer
17	EXIST	High intensive individualised training program with a focus on impact on physical fitness and fatigue	Adults	Multiple myeloma and lymphoma	Physical fitness and fatigue	Physio	Face-to-face	2	Still being researched	Research done / ongoing	Maxima Medical Centre
18	Onco-Move	Maintenance of physical fitness and reduction of fatigue during chemotherapy.	Adults		Physical fitness, fatigue, quality of life	Nurse	Face-to-face	1	Still being researched	Research done / ongoing	Integral Cancer Centre Netherlands
19	Online Menopausal Complaints	Reduction of menopausal complaints through internet based guided CBT.	Adults (women)	Breast Cancer	Sexuality issues, hot flushes, insomnia, night sweats	Psychologist Social worker	Online	1,2	Still being researched	Research done / ongoing	Netherlands Cancer Institute & MINDDISTRICT
20	On Track	Maintenance of muscular strength and cardio fitness and reduction of fatigue during chemotherapy.	Adults		Physical fitness, fatigue, quality of life	Physio	Face-to-face	1	Own institution and others	Research done / ongoing	VU University Medical Centre & Netherlands Cancer Institute & MOTION
21	AAF	Reduction of fatigue through ambulant activity feedback.	Adults	-	Fatigue	Physio	Online	2	Still being researched	Research done / ongoing	Roessingh Research & Rembrandt Paramedic Institute
22	Tele-Rehabilitation	Online support for 'homework' during multidisciplinary rehabilitation.	Adults	-	Fatigue, mental and physical functioning	Psychologist / Social worker Other caretaker	Blended	2,3	Own institution	Research done / ongoing	Roessingh Research and Rehabilitation Institute
23	Pain Signal (Pijnsein)	Improved pain control for cancer patients	Adults	-	Pain	Nurse	Face-to-face	5	No	Research done / ongoing	Radboud University Medical Centre
24	CBT Fatigue / Cancer	CBT for fatigue in cancer patients	Adults	-	Fatigue	Psychologist / Psychotherapist	Face-to-face	2	Own institution and others	Research done / ongoing	Radboud University Medical Centre
25	On the Road to Recovery	Online interventions to support recovery from fatigue.	Adults	Breast Cancer	Fatigue	Psychologist / Psychotherapist	Blended	2	Still being researched	Research done / ongoing	Radboud University Medical Centre / NKC

(continued)

Table 2. Continued.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
26	Throat Matters (Halszaken)	This guided self-help intervention aims to reduce speech, swallowing, and shoulder complaints of head and neck cancer patients during and after radiotherapy.	Adults	Head and Neck Cancer	Speech complications, swallowing complications, shoulder complaints	Physio Other caretaker	Blended	1	No	Research done / ongoing	VU University Medical Centre
27	REACT	Cardiorespiratory fitness and muscle mass training to reduce fatigue.	Adults	Various types of Cancer	Physical fitness and fatigue	Physio	Face-to-face	2	Own institution and others	Research done / ongoing	Maxima Medical Centre & VU University Medical Centre
28	Living without Vocal Cords	Guided self-help program to support head and neck cancer patients in dealing with the impact of their illness and its treatment.	Adults	Head and Neck Cancer	Complications with movement in head and neck area after surgery, nutrition, hygiene, speaking, prosthetics	Psychologist Nurse Physio Social worker Other caretaker	Blended	1,2	Still being researched	Research done / ongoing	VU University Medical Centre
29	Less Tired with Cancer	Online CBT therapy to reduce fatigue, insecurity, strong emotions and pain.	Adults		Fatigue	Psychologist / Psychotherapist	Online	2	Own institution	Research done / ongoing	Helen Dowling Institute
30	Recovery & Balance	Multidisciplinary rehabilitation care for patients	Adults		Various issues following cancer treatment	Psychologist Social worker Psychiatrist Other caretaker	Face-to-face	1,2,3	Own institution and others	Research done / ongoing	Integral Cancer Centre Netherlands
31	Program 'Balance'	Improving well-being during chemotherapy.	Adults		Fatigue, loss of fitness, psychosocial aspects, good nutrition	Physio Social worker Other caretaker	Face-to-face	1,3	Own institution	No research	Rijstate Hospital

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 3. Overview PO Interventions Category 3 – Cognitive functioning.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
32	Physical Training / Gloom	Intensive physical training to improve cognitive functioning.	Adults	Primary Brain Tumour	Cognitive issues, mood issues, quality of life, fatigue	Psychologist Physio Other caretaker	Online	2	Still being researched	Research done / ongoing	University Tilburg & Medical Centre Haaglanden & Erasmus Medical Centre & Netherlands Cancer Institute
33	ReMind	App for a cognitive rehabilitation program.	–	Primary Brain Tumour (Glioma)	Cognitive issues, mental fatigue	Other caretaker	Online	–	Still being researched	Research done / ongoing	University Tilburg & Mobiquit & Peter Boonstra
34	CogMed	Online training to improve the working memory.	–	–	Cognitive issues	Psychologist Other caretaker	Online	2	Own institution	Research done / ongoing	Pearson

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 4. Overview PO Interventions Category 4 – Pediatric/adolescent oncology.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
35	KLJK	Systematic monitoring and discussion of quality of life in chronically ill children.	Children, Adolescents Relatives	–	Quality of life, psychosocial functioning, communication	Psychologist Social worker Other caretaker	Online	1,2	Own	Research done / ongoing	Academic Medical Centre / Emma Children's Hospital
36	PRISMA	Neuro-feedback training to improve attention and memory.	Children, Adolescents	Brain Tumour	Information processing, focus, speed, memory	Other caretaker	Face-to-face	2	No	Research done / ongoing	Academic Medical Centre / Emma Children's Hospital & EEG Resource Institute
37	QLIM	Improvement of physical fitness to reduce health problems and increase quality of life.	Children, Adolescents	–	Fitness, muscle tone, quality of life	Psychologist Physio	Face-to-face	1,2	Still being researched	Research done / ongoing	Nijmegen VU University Medical Centre & University Medical Centre Utrecht
38	On Track	Course for children to learn how to better deal with the consequences of their illness.	Children, Adolescents	–	Late Effects	Psychologist Other caretaker	Face-to-face /Online	2	Own	Research done / ongoing	Academic Medical Centre / Emma Children's Hospital & Trimbos Institute
39	Cancer in the Family	Supporting children and their parents to deal with cancer in the family.	Children, Adolescents and their relatives	–	–	Psychologist Volunteer	Face-to-face	5	Own	No research	Toon Hermans Home & Mourning Service Atalanta

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 5. Overview PO Interventions Category 5 – Significant others.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
40	Load Thermometer	To more effectively support parents and children by making an inventory of issues.	Relatives (of children)	–	Difficulties and Distress	Psychologist Social worker	Face-to-face	5	Own institution and others	Research done / ongoing	Academic Medical Centre / Emma Children's Hospital Vilans
41	BrainSTARS	Education for parents, educators and others around acquired brain injury.	Relatives (of children)	Brain tumour, acquired brain damage	Damage consequences: social, emotional, cognitive	Psychologist Social worker Other caretaker	Face-to-face	2	Own institution and others	Research done / ongoing	Vilans
42	Parent Support	Support for parents with cancer to deal with their diagnosis and their role as a parent.	Relatives (of children)	–	–	Social worker	Face-to-face	5	Own institution	Research done / ongoing	Netherlands Cancer Institute
43	Hold on, for each other	Online support for next of kin.	Relatives	–	Fearfulness, sombreness, burden of long term care	Psychologist / Psychotherapist	Online	5	Still being researched	Research done / ongoing	University Twente & VU University Medical Centre
44	Grief Guidance for Next of Kin	Group sessions to support people who have lost a loved one.	Relatives	–	Storytelling, farewell, wellbeing	Psychologist Social worker Volunteer	Face-to-face	7	Own institution and others	No research	Toon Hermans Home & Amarant & Stade
45	Next of Kin Group	Grief support for partners.	Relatives	–	Grief, Loss	Social worker	Face-to-face	7	Own institution	No research	PISA Foundation
46	Partner Group	Support groups for partners of cancer patients.	Relatives	–	Tension, Reducing the burden	Social worker	Face-to-face	1,2,3	Own institution	No research	PISA Foundation

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 6. Overview PO Interventions Category 6 – Prevention, screening, and quality of life.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implement- ation	Research evidence	Provider / developer
47	Geriatric Navigator	Online screening tool with a focus on age-related problems in older cancer patients.	Adults	–	–	Nurse	Face-to-face	1,2,3	Own institution and others	Research done / ongoing	Integral Cancer Centre Netherlands & GeriOnE
48	Complex Care	Identifying issues with the patient and working with them on improvement.	–	–	False-positive results, failed surgery, medical mistakes	Psychologist Psychiatrist	Face-to-face	5	No	No research	VU University Medical Centre
49	ROGYcare	Developing a tailored care plan to improve quality of life.	–	Gynaecological Cancer	Information Provision	Nurse Other caretaker	Face-to-face	1,2	Still being researched	Research done / ongoing	Tilburg University

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 7. Overview PO Interventions Category 7 – Communication and patient information.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implement- ation	Research evidence	Provider / developer
50	My Question Aid	Online question aid to prepare for a first outpatient visit to the surgeon following oesophageal cancer.	–	Oesophageal Cancer	–	Other caretaker	Online	2	Still being researched	Research done / ongoing	Academic Medical Centre
51	GiOCA day	Online tool to prepare for hospital examinations.	Adults	Colorectal Cancer	–	–	Online	1	Own institution	Research done / ongoing	Academic Medical Centre, University of Amsterdam, GiOCA clinic
52	Patient Navigator	Support older (70+) patients by providing oversight, helping them prepare for hospital visits, decision making and practical support.	Adults	Colorectal Cancer	Overview Treatment Process	Nurse	Online	1,2	Still being researched	Research done / ongoing	Academic Medical Centre & University of Amsterdam & Haga Hospital
53	Palliative Care Decision	To support shared decision making on palliative chemotherapy.	Adults	Terminal Cancer	Decision Making around Palliative Chemo	Self-help	Online	3	Still being researched	Research done / ongoing	Academic Medical Centre
54	PatientTIME	Online self-help tool to support patients and help them prepare for consultations.	Adults	Non-Hodgkin Lymphoma	–	Self-help	Online	5	Own institution	Research done / ongoing	NIVEL Institute
55	Decision Making Support	To support decision making by providing insight into possible dilemmas.	Adults,	Adolescents Relatives	–	–	Social worker	Face-to-	face	1,2,3	Own institution
No research Netherlands Cancer Institute											

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 8. Overview PO Interventions Category 8 – Work and survivorship.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implement- tation	Research evidence	Provider / developer
56	A-WORK	To support cancer patients returning to work by discussing work related issues and promoting fitness.	-	-	Return to Work	Physio Other caretaker	Face-to-face	1,2	Own institution and others	Research done / ongoing	Academic Medical Centre
57	RE-CAP	To support return to work for cancer patients without a work contract.	Adults, Adolescents	-	Return to Work	Other caretaker	Face-to-face	2,3	Still being researched	No research	VU University Medical Centre & EMGO & Agens & Olympia

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 9. Overview PO Interventions Category 9 – Intimacy and sexuality.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
58	Sexual Rehabilitation	CBT based intervention to improve sexual recovery following radiotherapy	Adults	Gynaecological cancer with RT Radiation	(Prevention of) Sexuality Complications	Psychologist Nurse Other caretaker	Face-to-face	2	No	Research done / ongoing	Leiden University Medical Centre
59	KIS	Online CBT based intervention to reduce problems around sexuality and intimacy.	Adults (women)	Breast Cancer	Sexuality Complications	Psychologist	Online	2	No	Research done / ongoing	Netherlands Cancer Institute & Virenze

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 10. Overview PO Interventions Category 10 – Palliative care and end-of-life care.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implement- tation	Research evidence	Provider / developer
60	CBT Fatigue / Palliative Care	CBT and GET based intervention to reduce severe fatigue.	Adults	Breast Cancer Colorectal Cancer	Fatigue	Physio Psychologist	Face-to-face	3	Still being researched	Research done / ongoing	Radboud University Medical Centre

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 11. Overview PO Interventions Category 11 – Spirituality and meaning.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implementation	Research evidence	Provider / developer
61	Writing Helps	Use writing as a tool to address spirituality and resilience.	Adults	–	Existential Questions	Mental health carer	Face-to-face	2	Own Institution and others	No research	VU University Medical Centre & EMGO & Living With Cancer Research Group
62	Living after Cancer	Group therapy to address issues around life after cancer	–	–	Giving Meaning to Life	Psychologist / Psychotherapist	Face-to-face	2	Still being researched	Research done / ongoing	VU University Medical Centre & Ingeborg Douwes Centre
63	What Inspires You?	To discuss in a group source of inspiration to address fundamental questions.	–	–	Existential Questions	Psychologist Social worker Volunteer	Face-to-face	–	Own Institution	No research	Toon Hermans Home & Amarant
64	Haptonomic Guidance	To support patients in reconnecting with their body.	–	–	Aversion to Marred Body	Psychologist Other caretaker	Face-to-face	5	Own Institution and others	No research	Helen Dowling Institute

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

Table 12. Overview PO Interventions Category 12 – Genetics.

Nr	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ²	Implementation	Research evidence	Provider / developer
65	Family Counseling	To support patients on informing relatives.	Adults	Breast Cancer, Gynaecological Cancer, Colorectal Cancer	Informing Family around hereditary cancer	Social worker Other caretaker	Face-to-face	6	Still being researched	Research done / ongoing	Academic Medical Centre
66	Signal	To facilitate conversations around genetic issues with counsellors.	Adults	–	Social Issues around genetics	Other caretaker	Face-to-face	6	Still being researched	Research done / ongoing	Netherlands Cancer Institute

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.

^aTarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).

^bIllness Phase: (1) diagnosis/treatment; (2) after the treatment; (3) palliative phase; (4) terminal phase; (5) all phases; (6) genetic testing; (7) after passing away of relative.

focused on types of cancer with quite specific side effects, e.g., cognitive rehabilitation following a brain tumor. Interventions where the type of cancer was not specified were mostly submitted from clinical practice.

Focus area

Interventions were not always developed around one problem or complaint. Often a combination of complaints (e.g., depressive complaints, distress, and anxiety) was addressed. Ten of the 16 interventions (63%) in the 'Physical functioning and recovery' category targeted fatigue. The next most frequent addressed area was physical fitness and recovery of stamina. Interventions on cognitive problems appeared to focus on general issues (e.g., concentration problems). Interventions for children and young adults focused on a broad range of issues around having cancer. In the category 'Communication and patient information', equal attention was paid to the treatment process in general and interventions focusing on shared decision making or decision-making support. Sexuality interventions focused exclusively on breast and gynecological cancer and appear to be limited to women as a target group.

Health care provider

A pre-coded question asked about which caregivers were involved with the intervention, either in the development or the delivery. A psychologist was most frequently mentioned (34 times, 52%), followed by a social worker (20 times, 30%) and a physiotherapist (17 times, 26%). In 22 cases, the option 'other' was chosen, indicating it was not one of the professionals specified. Mostly, this other caregiver was a medical specialist (15 times, 22%).

Notably, there was more than one health care professional involved with nearly half of the interventions (44%), indicating a multidisciplinary approach.

Intervention type

Face-to-face was the most common delivery method of an intervention (40 times, 61%), followed by online delivery (15 times, 23%) and blended methods (8 times, 12%).

Illness phase

The majority of interventions focused on the time following treatment (42 times, 64%) followed by the diagnosis and treatment phase (20 times, 30%).

Five interventions could be applied in any phase, and no intervention aimed specifically at the terminal phase.

Implementation

In a pre-coded question, participants were asked to indicate if their intervention is offered to clients and to what degree. Thirty-eight interventions (58%) had been implemented in clinical practice. Of these, 16 were only implemented in the own institution, 22 were also available in other institutions. Twenty interventions (71%) were offered to patients as part of a research context.

Evidence

Information provision on available evidence was very much dependant on the information submitted. For the purpose of this paper, the provided information was summarized to: (1) (currently) researched (51 times, 77%) or (2) no (current) research (15 times, 23%). In the first group, for 49% (25 interventions), it was indicated that research regarding the evaluation of the effectiveness of the intervention was still ongoing, for 43% (22 interventions), it was indicated that the intervention had been evaluated, but with a different patient group. Only in four interventions (8%), the effectiveness of the intervention already had been established. In the second group, no evidence for effectiveness was present nor had it been researched.

Provider/developer

Most of the interventions were developed and offered by (academic) cancer research centers. Eleven times, collaboration was mentioned with other parties, such as a local hospital or care practice.

Discussion

Main findings

This study provides a first overview of PO-interventions that is accessible to patients, researchers, grant providers and health care workers alike through open access. In summary, the 66 identified PO-interventions: (1) focus for the majority (63%) on depressive complaints, anxiety, and distress; (2) focus for 24% on physical functioning and recovery, of which 63% is aimed at reducing fatigue and 37% at improving physical fitness and improvement of physical stamina; (3) are frequently not aimed at a

specific type of cancer (61%); (4) are mostly directed at adults (65%); (5) are executed by or in collaboration with a psychologist (52%); (6) are not yet nationally available for patients, but only at a local or regional level; (7) are mostly developed in reputable research institutes; and (8) lack scientific underpinning in nearly 25% of the cases.

Interpretation of findings

This first overview allowed for a reflection on the development of PO-interventions.

Categorizing interventions

The majority of interventions were included in the first two categories, i.e., ‘Psychosocial functioning’ and ‘Physical functioning and recovery’, and together they account for nearly 50% of all interventions. It could be argued that these are quite broad groups that warrant further refinement. At the same time, all interventions in the first category deal with anxiety, distress and depression, which are all clearly psychological issues. While adjustment of the name of the category (into ‘Psychological functioning’) probably would be in place, it is obvious that these issues should have top priority when it comes to support for cancer patients and survivors. Comparably, with regard to ‘Physical functioning and recovery’, the number of interventions in this category reflects one of the main problems cancer patients and survivors acknowledge: fatigue. Numerous previous studies have shown the effectiveness of physical activity on several physical and psychosocial outcomes, such as fatigue,²² which explains the volume of the group.

Rationale for development of interventions

It is not clear what the rationale is for developing a specific PO-intervention. For example, ‘Physical functioning and recovery’ is a well-acknowledged and well-established problem area. Does the high number of interventions in this area tell us that this is an area with most issues, an area where improvements still can be made²³, or maybe even an area with ample funding opportunities? Further research is necessary to answer these questions. This may help researchers, policymakers and grant providers in making informed decisions around new developments.

Similarly, some areas appear to be underdeveloped. For example, in this overview, there were no PO-interventions focusing on male sexuality, while both testicular cancer and prostate cancer can result in major sexuality issues.²⁴ An explanation could be that problems may be less prominent, or

less addressed by health care professionals, or because these interventions are harder to develop and test, because of the number of patients and survivors willing to participate in such studies. Another example is the lack of interventions specifically focusing on the terminal phase. Maybe, there are sufficient generic interventions available, providing less of an incentive to develop new interventions, but there is also a chance that there may be difficult ethical issues around research in this phase.²⁵

Effectiveness of interventions

This first inventory highlighted issues around an evidence base for the effectiveness of interventions. Based on the material presented to us, nearly 25% of the interventions lacked a substantial evidence base and 20 interventions were offered within the context of ongoing scientific studies. At the same time, research shows that interventions that have gone through the extensive process of a randomized controlled trial, fail to find their way into clinical care. Limitations of the trial, e.g., inadequate patient inclusion, may result in a lack of power to establish positive effects of the intervention, but also financial issues or insufficient knowledge about the implementation process may cause an intervention to end up on a bookshelf.²⁶

Parameters needed

Both the lack of a rationale in developing interventions and the scant evidence into effectiveness indicate that there may be a lack of parameters guiding development. For example, if there are 20 interventions for cancer-related fatigue, what would be the rationale for developing a new one? Or is the magnitude in itself cause for review? Similarly, it could be argued that interventions, once validated for certain populations or types of cancer, can be rolled out to other groups, without additional research. There is a lack of quality criteria around evidence. Adopting the Cochrane classification (<http://consumers.cochrane.org/levels-evidence>) to establish the strength of the evidence may provide a way forward.

Developments in research and in clinical practice

This overview considered the connection between research and practice as two-way traffic. This resulted in almost equal numbers of submissions from practice and from research. However, many more submissions from practitioners were rejected, mostly because the interventions were too strongly linked to a sole practitioner, lacked an evidence base, and were not scalable. Therefore, collaboration between clinicians, researchers and patients, and patient organizations is highly recommended, as well as an emphasis on co-creation.²⁷

Limitations and strengths

This study provides a first overview of interventions, not a rigorous assessment of scientific evidence and effectiveness, as this was not the purpose of this inventory. Now the groundwork of an overview and a definition of PO-intervention is done, a next step would be to investigate the evidence and effectiveness of these interventions as well as fine-tune the definition.

This one-off inventory provides a snapshot, as developments will be ongoing and therefore a repeat exercise may be judicious also because some time has passed since this inventory was undertaken. There may have been selection bias in the sampling method as psychologists were the most frequently involved group of professionals. Psychologists are the largest professional group within the NVPO, and departments of medical psychology in hospitals were emailed directly.

In this overview, we have decided to focus on oncology-specific interventions, thus excluding generic interventions, such as CBT. However, it was found that these kinds of generic interventions were at the basis of a number of interventions included in this overview. We would recommend that a next study addressed this in more detail. Finally, the patient's perspective was not considered in this project. That said, the structured approach of this study is a strength, and it provides a template for a similar exercise in other jurisdictions, thus developing our understanding of PO-interventions.

Conclusions

This first inventory into PO-interventions has resulted in an open access overview of 66 interventions (http://issuu.com/nvpo/docs/interventies_in_de_psychosociale_on?e=14606812/13589166, in Dutch). This overview provides input into a discussion about the development of PO-interventions, to increase accessibility and wider implementation of PO-interventions. The inventory shows that we are very much at the start of validating and defining the field of PO-interventions. There is very little knowledge on what constitutes a good PO-intervention and on actual supply and demand. Equally, there is limited reflection on what drives the development of interventions and on under- or overdevelopment in certain problem areas. A next step would be to conduct a study to investigate the effectiveness and evidence of PO-interventions. This will also address enablers and barriers of implementing PO-interventions in practice. Done across different jurisdictions, this may highlight differences between countries in how care is organized and financed. Ultimately, the focus should be on the integration of PO-care in oncological care, making the signaling of complaints and referral to appropriate care standard practice.¹⁴ For integrated care,

awareness and involvement of medical professionals is essential.¹⁷ We see the fact that medical professionals were involved in 15 of the interventions in this overview as a positive signal towards the move to integrated care.

Disclosure statement

Authors do not have a financial relationship with the grant provider. Authors have full control of all primary data and agree to allow the journal to review the data if requested.

Data availability statement

Data for this study is accessible via https://issuu.com/nvpo/docs/interventies_in_de_psychosociale_on

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