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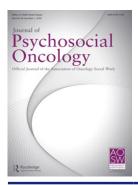
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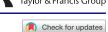
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ARTICLE



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 POinterventions 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:

- 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 where 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

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ž	Name	Aim	group ^a	Type of cancer	Focus area	care provider	type	phase ^b	tation	evidence	Provider / developer
-	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 Physio Social worker Psychiatrist	Face-to- face /online	2	Own institution and others	Research done / Helen Dowling ongoing Institute an Radboud University Medical Cer	Helen Dowling Institute and Radboud University Medical Centre
7	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 after treatment	Social worker Nurse Face-to-face Other caretaker	Face-to-face	2	Own institution	Research done / ongoing	Integral Cancer Centre Netherlands and Home Care Drenthe
m	3 I-MBCT	Reduction of depressive symptoms by teaching patients other ways to deal with stressful situations	Adults	1	Depressive symptoms Psychologist /Psychoth	Psychologist /Psychotherapist	Face-to-face	2	Own institution and others	Research done / ongoing	Research done / University Medical ongoing Centre Groningen
4	Problem Solve Training	Improve well-being through helping patients address stressful situations differently	Adults	ı	1	Psychologist /Psychotherapist	Face-to-face	1,2	Own institution and others	Research done / ongoing	Research done / University Medical ongoing 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	Research done / Radboud University ongoing Medical Centre
9	MBSR /MBCT	Group training to reduce fear and depression complaints and increase acceptance and quality of life.	1	ı	quality	Physio rker st		1,2,3	Own institution and others	Research done / Jon Kabal-Zinn, ongoing University of Massachuset USA (MBSR)	Jon Kabal-Zinn, University of Massachusetts, USA (MBSR)
_	7 Learning to live with fear	Aims to teach patients with a Adults 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	7	Still being researched	Research done / ongoing	Research done / Radboud University ongoing Medical Centre

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ž	. Name	Aim	group ^a	Type of cancer	Focus area	care provider				evidence	Provider / developer
∞	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	1	Nurse	Face-to-face	2	Own institution	Research done / ongoing	Research done / University Medical ongoing Centre Utrecht & Julius Centre
9	Distress / Colorectal Cancer	Early detection and if needed Adults treatment of psychosocial distress following a stepped-care approach	Adults	Colorectal Cancer	Distress	Psychologist Nurse Psychiatrist	Blended	-	No	Research done / VU University ongoing Medical Ce GGZ Ingee	VU University Medical Centre & GGZ Ingeest
10	10 Stepped Care Distress	Reduction of psychological distress.	Adults	Haematological Distress Cancer	Distress	Physio	Blended	2	No No	Research done / VU University ongoing Medical Ce GGZ Ingee	VU University Medical Centre & GGZ Ingeest
Ξ	11 Relaxation and Meditation (Ontspanning en Meditatie)	Course to learn to be mindful in the present amidst the chaos that cancer can cause.	ı	I	Stress, fatigue, fearfulness, emotions	Psychologist Social worker Volunteer	Face-to-face	ı	Own institution and others	No research	Toon Hermans Home & Amarant
12	12 Continuing after Cancer (Kanker en nu verder)	Group sessions to share experiences around the cancer process.	ı	1	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	13 Reduced Fear around Cancer (Minder angst bii kanker)	Online self-help tool to reduce fear of recurrence.	Adults	I	Fear of relapse	Psychologist / self-help	Online	7	Own institution	Research done / Helen ongoing Do	Helen Dowling Institute
4	Therapeutic Weeks (Therapeutische weken)	14 Therapeutic Weeks Group treatment around (Therapeutische emotional recuperation weken) following cancer diagnosis and treatment.	Adults, Relatives	1	Cancer related issues	Psychologist Physio Face-to-face Other caretaker		2,3	Own institution	No research	Les Vaux Foundation
15	15 Guidance with Loss of Health (Begeleiding gezondheids- verlies)	Support patients in their grieving process.	Adults, Relatives	1	1	Social worker	Blended	7	Own institution	No research	Netherlands Cancer Institute
16	16 Continuity Visits	Continuous support in an intensive period of bad news and ongoing treatment.	Adults	1	-	Nurse	Face-to-face 1,2,3	1,2,3	Own institution and others	Research done / ZorgSaam ongoing Zeeuws Vlaand	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.

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ž	Name	Aim	Target group ^a	Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implemen- tation	Research evidence	Provider / developer
17	17 EXIST	High intensive individualised training program with a focus on impact on physical fitness and fatioue	Adults	Multiple myeloma and lymphoma	Physical fitness and fatigue	Physio	Face-to-face	7	Still being researched	Research done / ongoing	Maxima Medical Centre
18	18 Onco-Move	Maintenance of physical fitness and reduction of fatigue during chemotherapy.	Adults		Physical fitness, fatigue, quality of life	Nurse	Face-to-face	-	Still being researched	Research done / ongoing	Integral Cancer Centre Netherlands
19	19 Online Menopausal Complaints	Reduction of menopausal complaints through internet based quided 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	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	-	Own institution and others	Research done / ongoing	VU University Medical Centre & Netherlands Cancer Institute & MOTION Physiotherapy
21	21 AAF	Reduction of fatigue through ambulant activity feedback.	Adults	1	Fatigue	Physio	Online	7	Still being researched		Roessingh Research & Rembrandt Paramedic Institute
22	Tele-Rehabilitation	22 Tele-Rehabilitation Online support for 'homework' during multidisciplinary rehabilitation.	Adults	1	Fatigue, mental and physical functioning	Psychologist Physio Blended Social worker Other caretaker	Blended	2,3	Own institution	Research done / ongoing	Roessingh Research and Rehabilitation
23	23 Pain Signal (Pijnsein)	Ē	Adults	I	Pain	Nurse	Face-to-face	٠,	ON.	Research done / ongoing	Radboud University Medical Centre
24	24 CBT Fatigue / Cancer	CBT for fatigue in cancer patients	Adults	I	Fatigue	Psychologist / Psychotherapist	Face-to-face	2	Own institution and others	Research done /	Radboud University Medical Centre
25	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 / NKCV
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ž	Name	Aim	Target group ^a	Target group ^a Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Implemen- tation	Research evidence	Provider / developer
56	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.		Head and Neck Cancer	Speech complications, swallowing complications, shoulder complaints	Physio Other caretaker	Blended	-	0	Research done / ongoing	VU University Medical Centre
27	27 REACT	Cardiorespiratory fitness and muscle mass training to reduce fatigue.	Adults	Various types of Cancer	Physical fitness and fatigue	Physio	Face-to-face	7	Own institution and others	Research done / ongoing	Maxima Medical Centre & VU University Medical Centre
28	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	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	30 Recovery & Balance	ilita	ion Adults		Various issues following cancer treatment	Psychologist Physio 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'	 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.

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Nr Name	ame	Aim		Target group ^a Type of cancer	Focus area	Health care provider	Intervention type	Illness phase ^b	Intervention Illness Implemen- type phase ^b tation		Research evidence Provider / developer
32 Physical 7	Training / m	32 Physical Training / Intensive physical training to Glioom improve cognitive	Adults	Primary Brain Tumour	mary Cognitive issues, Brain Tumour mood issues,	Psychologist Physio Online Other caretaker	Online	2	Still being	Research done /	University Tilburg & Medical Centre
		functioning.			quality of life, fatique				researched	ongoing	Haaglanden & Erasmus Medical
											Centre &
											Netnerlands Cancer Institute
33 ReMind		App for a cognitive	1	Primary Brain	Cognitive issues,	Other caretaker	Online	1	Still	Research	University Tilburg &
		rehabilitation program.		Tumour	mental fatigue				being	done /	Mobiquit &
				(Glioma)					researched	ongoing	Peter Boonstra
34 CogMed		Online training to improve	1	1	Cognitive issues	Psychologist	Online	7	Own	Research	Pearson
		the working memory.				Other caretaker			institution	done /	
										ongoing	

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

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ž	Name	Aim	Target group ^a	cancer	Focus area	care provider	type phase ^b	phase ^b	tation	evidence	Provider / developer
35 KLIK		Systematic monitoring and discussion of quality of life in chronically ill children.	Children, Adolescents Relatives	I	Quality of life, psychosocial functioning,	Psychologist Social worker Other caretaker	Online	1,2	Own institution and others	Research done / ongoing	Academic Medical Centre / Emma Children's
36 PRISMA	۷	Neuro-feedback training to improve attention and memory.	Children, Adolescents	Brain Tumour	Information processing, focus, speed, memory	Other caretaker	Face-to-face	7	° 2	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	1	Fitness, muscle tone, quality of life	Psychologist Physio Face-to-face	Face-to-face	1,2	Still being researched	Research done / ongoing	VU University Medical Centre & University Medical
38 On Track	ack	Course for children to leam how to better deal with the consequences of their illness.	Children, Adolescents	ı	Late Effects	Psychologist Other caretaker	Face-to- face /Online	7	Own institution and others	Research done / ongoing	Academic Medical Centre / Emma Children's Hospital & Trimbos Institute
39 Cancer in the Far	ncer in the Family	Supporting children and their parents to deal with cancer in the family.	Children, Adolescents and their relatives	ı	1	Psychologist Volunteer	Face-to-face	5	Own institution and others	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.

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

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.

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ž	Name	Aim	Target group ^a Type of cancer	Type of cancer	Focus area	care provider	type	phase	tation	evidence	evidence Provider / developer
47	Geriatric Navigator	17 Geriatric Navigator Online screening tool with a	Adults .		ı	Nurse	Face-to-face 1,2,3 Own	1,2,3		Research	Integral Cancer
		focus on age-related							institution	done /	
		problems in older							and others	ongoing	Netherlands
		cancer patients.									& GeriOnE
48	48 Complex Care	Identifying issues with the	1	1	False-positive results, Psychologist	Psychologist	Face-to-face	2	No	No research	≾
		patient and working with			failed surgery,	Psychiatrist					Medical Centre
		them on improvement.			medical mistakes						
49	49 ROGYcare	Developing a tailored care	1	Gynaecological	Information Provision Nurse	Nurse	Face-to-face 1,2	1,2	Still	Research	Tilburg University
		plan to improve quality		Cancer		Other caretaker			being	done /	
		of life.							researched	ongoing	

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.

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					Health	Intervention	Illness	Implemen-	Research	
Nr Name	Aim	Target group ^a	Type of cancer	Focus area	care provider	type	phase ^b		evidence	Provider / developer
50 My Question Aid	O	ı	Oesophageal Cancer	ı	Other caretaker	Online	2	Still being researched	Research done / ongoing	Academic Medical Centre
51 GIOCA day	oesophageal cancer. Online tool to prepare for hospital examinations.	Adults	Colorectal Cancer –		1	Online	-	Own institution	Research done / ongoing	Academic Medical Centre, University of Amsterdam,
52 Patient Navigator	by providing oversight, helping them prepare for hospital visits, decision making and a making and provided to making and provided to more than the provided to making and the marker of the provided to making and the marker of	Adults	Colorectal Cancer Overview Treatn	Vverview Treatment Process	Nurse	Online	1,2	Still being researched	Research done / ongoing	Academic Medical Centre &University of Amsterdam & HAGA Hospital
53 Palliative Care Decision	ř	Adults	Terminal Cancer	Decision Making around	Self-help	Online	м	Still being	Research done /	Academic Medical Centre
54 PatientTIME	Online Self-help to only to self-help to only them prepare for consultations.	Adults	Non- Hodgkin Lymphoma		Self-help	Online	2	Own	Research done / ongoing	NIVEL Institute
55 Decision Making Support No research	To support decision making by providing insight into possible dilemmas. Netherlands Cancer Institute	Adults,	Adolescents Relatives	1	1	Social worker	Face- to-	face	1,2,3	Own institution

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.

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ž	. Name	Aim	Target group ^a	Type of cancer	Type of Target group ^a cancer Focus area	Health Intervention Illness Implemen- Research care provider type phase ^b tation evidence	Intervention type	Illness phase ^b	Implemen- tation	Research evidence	Research evidence Provider / developer
56	56 A-WORK	To support cancer patients returning to work by discussing work related	ı	ı	Return to Work Physio Othe	Physio Other caretaker	Face-to-face 1,2 Own institution and others	1,2	Own institution and others	Research done / ongoing	Academic Medical Centre
		issues and promoting fitness.								n n	
27	57 RE-CAP	To support return to work for Adults,	Adults,	ı	Return to Work	Return to Work Other caretaker	Face-to-face	2,3	Still	No research	VU University
		cancer patients without a	Adolescents						being		Medical Centre &
		WOIR COILIACL							ובאבשורוובת		& 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.

						Health	Intervention	Illness	Implemen-	Research	
ž	Nr Name	Aim	Target group ^a	Farget group ^a Type of cancer	Focus area	care provider	type phase ^b tation	phase ^b	tation	evidence	Provider / developer
58 Sexual	exual	CBT based intervention to	Adults	Gynaecological	(Prevention of)	Psychologist Nurse Face-to-face	Face-to-face	2	9 N	Research	Leiden University
	Rehabilitation	improve sexual recovery		cancer with		Other caretaker				done /	Medical Centre
		following radiotherapy		RT Radiation	Complications					ongoing	
S9 KIS	SI	Online CBT based	Adults	Breast Cancer	Sexuality	Psychologist	Online	7	No	Research	Netherlands Cancer
		intervention to reduce	(women)		Complications					done /	Institute
		problems around sexuality								ongoing	& Virenze
		and intimacy									

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

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

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

t- General: (PO) Psychosocial Oncology, (-) not specified/not applicable.
 a flarget group: This has in the table been reduced to four groups: adults, (women), adolescents, children, and relatives (including relatives of children with cancer).
 b fliness 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.

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			Target	Type of		Health	Intervention Illness	Illness	Implemen-	Research	
ž	Name	Aim	group ^a	cancer	Focus area	care provider	type	phase ^b	tation	evidence	Provider / developer
61	Writing Helps	Use writing as a tool to	Adults	ı	Existential Questions	Mental health carer Face-to-face	Face-to-face	2	Own	No research	VU University
		address spirituality							institution		Medical Centre &
		and resilience.							and others		EMGO & Living
											With Cancer
											Research Group
62	Living after Cancer	62 Living after Cancer Group therapy to address	1	1	Giving Meaning	Psychologist /	Face-to-face	7	Still	Research	VU University
		issues around life			to Life	Psychotherapist			being	done /	Medical Centre &
		after cancer							researched	ongoing	Ingeborg
											Douwes Centre
63	What Inspires You?	63 What Inspires You? To discuss in a group source	1	1	Existential Questions	Psychologist Social	Face-to-face	ı	Own	No research	Toon Hermans Home
		of inspiration to address				worker			institution		& Amarant
		fundamental questions.				Volunteer					
64	64 Haptonomic	To support patients in	ı	1	Aversion to	Psychologist	Face-to-face	2	Own	No research	Helen
	Guidance	reconnecting with			Marred Body	Other caretaker			institution		Dowling Institute
		their body.							and others		

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.

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		Target		Health	Intervention	Illness	Intervention Illness Implemen-	Research	
Nr Name	Aim	group ^a Type of cancer	Focus area	care provider	type	phase2	phase2 tation	evidence	Provider / developer
65 Family Counseling	65 Family Counseling To support patients on	Adults Breast Cancer,	Informing Family	Social worker	Face-to-face 6	9	Still		Academic
	informing relatives.	Gynaecological	around	Other caretaker			being	done /	Medical Centre
		Cancer,	hereditary cancer				researched	ongoing	
		Colorectal Cancer							
66 Signal	To facilitate conversations	Adults –	Social Issues	Other caretaker	Face-to-face	9	Still	Research	Netherlands
	around genetic issues with		around genetics				being	done /	Cancer Institute
	counsellors.						researched	ongoing	

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, evidence for effectiveness was present nor 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 POinterventions.

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 cancerrelated 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 classifica-(http://consumers.cochrane.org/levels-evidence) to establish 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 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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