




OPEN ACCESS

Cancer centre information and support services and patient needs: participatory action research study

Helen P A Driessen ¹, Jan J V Busschbach,¹ Erna J Elfrink,² Carin C D van der Rijt,³ Gabriël M R M Paardekooper,⁴ Corine J den Hollander,⁵ Leonieke W Kranenburg¹

¹Department of Psychiatry, Section of Medical Psychology and Psychotherapy, Erasmus Medical Center, Rotterdam, The Netherlands

²Erasmus MC Cancer Institute, Erasmus Medical center, Rotterdam, The Netherlands

³Department of Medical Oncology, Erasmus Medical Center, Rotterdam, The Netherlands

⁴Department of Radiotherapy, Isala Oncology Center, Zwolle, The Netherlands

⁵Institutions Psychosocial Oncology (IPSO)-center IntermeZZo, Zwolle, The Netherlands

Correspondence to

Helen P A Driessen, Department of Psychiatry, Section of Medical Psychology and Psychotherapy, Erasmus Medical Center, Rotterdam 3000 CA, The Netherlands; h.driessen@erasmusmc.nl

Received 30 June 2023

Accepted 3 February 2024



© Author(s) (or their employer(s)) 2024. Re-use permitted under CC BY-NC. No commercial re-use. See rights and permissions. Published by BMJ.

To cite: Driessen HPA, Busschbach JJV, Elfrink EJ, et al. *BMJ Supportive & Palliative Care* Epub ahead of print: [please include Day Month Year]. doi:10.1136/spcare-2023-004464

ABSTRACT

Objectives Clear information and supportive care are necessary for oncology patients and their relatives to manage the disease (trajectory). Centres for information and support aim to address their needs by offering informal and non-medical formal services. This study evaluated whether the centres' services offered meet the needs of its visitors, and whether there is interest for these among oncology patients treated at affiliated hospitals.

Methods In this participatory action research, interviews were conducted among visitors of two centres (Patient Information Center Oncology (PATIO) and IntermeZZo) and among patients treated at the affiliated hospitals. Visitors were interviewed to share their experiences regarding the centres' services offered. Patients from the hospitals were interviewed about their interest in such support. Data were collected during three different periods and adjustments were made to the centres' services between measurements.

Results 111 (PATIO) and 123 visitors (IntermeZZo) were interviewed, and 189 and 149 patients at the respective hospitals. Reasons to visit PATIO/IntermeZZo were to relax (93.1%), seek professional advice (54.6%) and meet peers (36.3%). Visitors indicated that the visits met their needs (99.1%), citing the accessible support and the expertise in oncology. 20% of patients interviewed at the hospitals expressed interest in visiting PATIO/IntermeZZo. The majority of patients (89.6%) considered these centres an integral part of their treatment process. These findings were stable over time.

Conclusions Patients and their relatives highly value the services of hospital-affiliated centres for information and support. Future research should address how such centres best be integrated in the Dutch healthcare system.

WHAT WAS ALREADY KNOWN?

- ⇒ Patients and their relatives experience unmet needs in dealing with cancer.
- ⇒ Centres for information and support are developed to meet these needs and offer various types of informal care and non-medical formal care in close proximity to hospitals.

WHAT ARE THE NEW FINDINGS?

- ⇒ Centres for information and support have added value in a group of patients and their relatives: the visitors' needs and expectations are met by the various services of centres for information and support.
- ⇒ Patients with cancer consider the centres important initiatives and believe they should be integrated into the treatment trajectory; one-fifth of them is interested in using the centres' services.

WHAT IS THEIR SIGNIFICANCE

- ⇒ This study expands our understanding of the ways to address the needs of oncology patients and their relatives, taking into account the increasing demand for, and costs of, formal care in the future.
- ⇒ Centres for information and support have the potential of added value for both patients, their relatives and healthcare providers: these centres can tailor the care provided to the personal needs of its visitors and are less restricted to limited resources and time, in contrast to formal care.
- ⇒ Continuously creating awareness among healthcare providers is necessary to ensure that patients with cancer and their relatives, who feel the need for such support, can profit from these services.

INTRODUCTION

A recent survey by the Dutch Federation of Cancer Patients Organizations (NFK) showed that at least 25% of Dutch

patients with cancer experience insufficient support of the hospital during, but especially after, the treatment trajectory. 4309 patients surveyed mentioned the lack of emotional support and support for their relatives.¹ 68% of these patients indicated that they did feel the need to receive information regarding various types of supportive care, whereas 30% of the patients indicated that they had not received any such information during their trajectory.¹ Moreover, recent studies found that the patients' relatives also report the need for information and support, as they experience emotional distress, lack experience and information on providing support, face shifting caregiving roles and responsibilities, and fear losing their loved one.²⁻⁶

Another study focusing on the unmet care needs of 1103 Dutch patients with advanced cancer and their 831 relatives found that the unmet care needs of both patients and their relatives most often consisted of psychological issues, mainly fears and worries, followed by a range of issues within multiple domains of life, for example, informational needs, autonomy and spiritual issues.⁷ Thus, the unmet needs are not restricted to items related to medical care. Centres for information and support can play a role in fulfilling these unmet needs, as they offer both informal and non-medical formal supportive care, complementary to the medical formal care provided by the hospital. Examples of informal care include the provision of company, a listening ear and practical assistance by trained volunteers, the opportunity to meet peers and share experiences, and to attend creative workshops. In these centres, so-called support consultants offer basic psychoeducation, information and advice on non-medical matters, that is, non-medical formal supportive care.⁸ In case targeted referral to medical care is indicated, the support consultants assist the patient in this referral process as they cooperate with healthcare providers. Examples of Dutch centres for information and support are PATIO (Patient Information Center Oncology) and IntermeZZo. PATIO was opened by the Erasmus MC Cancer Institute, Rotterdam, in January 2019, and IntermeZZo, affiliated with the Isala Oncology Center in Zwolle, was opened in February 2010.

It can be hypothesised that these centres combine the beneficial effects of the multiple types of informal care and non-medical formal care provided, together with the closeness to formal care. A recent review highlighted the potential added value of such initiatives in coping with cancer diagnosis, treatment and its consequences.⁹ More than half of the included studies in this review (10/18) described initiatives that provided supportive care to anyone affected by (the consequences of) the disease, for example, oncology patients, relatives and friends. However, nearly all of these studies only focused on the experiences of patients with cancer, and only two studies also explicitly focused on the experiences of relatives.^{10,11} Moreover,

nearly all studies (17/18), only included patients who found their way to the initiatives, potentially leading to a positive bias among these 'users' compared with 'non-users'. There has been no detailed investigation described in literature of such 'non-users' and their knowledge and interest for this type of support.

Consequently, the aims of the current study were to investigate: (1) to what extent PATIO and IntermeZZo meet the needs for supportive care of its visitors, that is, patients, family members and friends and (2) the interest for the services of PATIO and IntermeZZo among oncology patients treated at the Erasmus MC Cancer Institute and the Isala Oncology Center.

METHODS

Study design and procedure

This participatory action research was conducted at the Erasmus MC Cancer Institute, a university hospital, and the Isala Oncology Center, a regional hospital. Participatory action research is a collaborative approach involving both researchers and patients in the investigation of a specific issue, with the aim of finding solutions or improving conditions. It is characterised as a cyclical process that commences with the diagnosis of problem situations, followed by the planning of action steps, implementation and evaluation of outcomes that in turn lead back to reassessment based on data collected.^{12,13} Within this approach, we conducted semistructured interviews and categorised the responses using predefined options. Semistructured interviews were conducted among visitors of the affiliated centres for information and support and the outpatient treatment departments of these hospitals. A flow chart of the study procedures is presented in figure 1. One interviewer (HPAD) interviewed visitors of PATIO and IntermeZZo. Interviews were conducted at PATIO or IntermeZZo, or by phone. Further, patients who were receiving treatment, that is, immunotherapy, chemotherapy and blood transfusion, at the outpatient treatment departments of the affiliated hospitals were interviewed by the same interviewer. Data were collected during three different periods between July 2020 and February 2022. Based on the results of each measurement, adjustments to the practice of the centres were made in the following period. These adjustments were then explicitly evaluated in the subsequent period of data collection.

Study population and setting

All visitors, that is, patients with cancer, their relatives and others involved, visiting PATIO or IntermeZZo during the specific study periods were eligible for inclusion. Included were all visitors willing to participate and present at the centres when the executive researcher (HPAD) was on-site, irrespective of whether they had previously been interviewed at an earlier time of data collection. In cases where the executive researcher was conducting interviews with

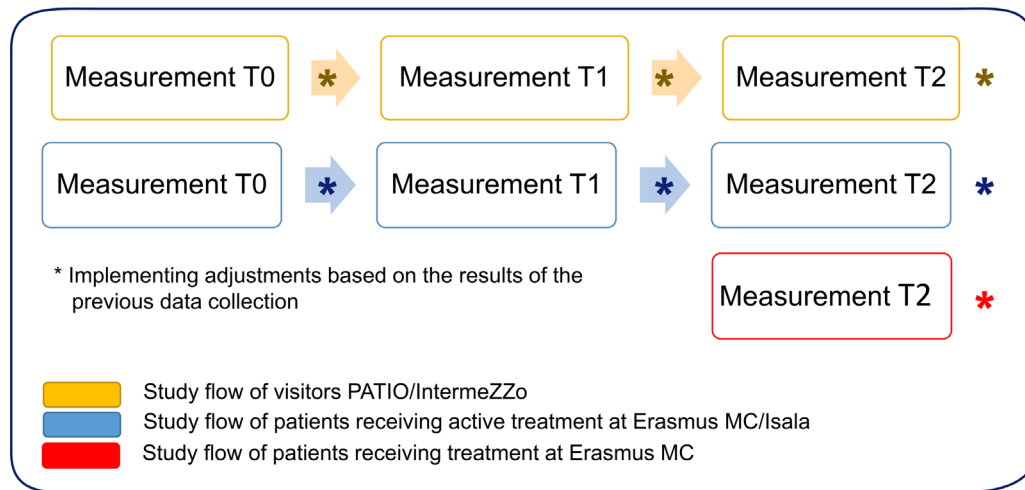


Figure 1 : Flowchart of study procedures

different visitors, those willing to participate had the option to provide their personal information and were subsequently interviewed at a later point in time. Moreover, all oncology patients who were treated at the outpatient treatment centres of the Erasmus MC Cancer Institute or the Isala Oncology Center were eligible for participation. Because of the large number of patients being treated simultaneously at the outpatient centres, as many individuals as possible were randomly approached by the executive researcher and were invited to participate. Included were all patients willing to participate at the time they were undergoing treatment and patients could participate regardless of whether they had previously been interviewed or had visited the centres previously. During the last round of interviews, patients who visited the outpatient department of Erasmus MC Cancer Institute for follow-up consultations after being treated with curative therapy, or patients in the palliative phase of the disease trajectory were also eligible for the interview study. The purpose of this extra group was to gain insight into whether patients in a different stage of the disease had any interest in visiting PATIO, and whether they have had any interest to visit PATIO in retrospect, namely during the active phase of their disease trajectory.

Description of care provided at PATIO and IntermeZZo

The informal services of the centres include supportive talks with volunteers, offering a lounge for visitors to rest and wait between appointments, extensive information sessions, workshops, individual treatments and individual coaching (all categorised as ‘relaxation’). Additionally, there is an opportunity to connect with peers via organised meetings or during workshops (categorised as ‘meeting peers’). The centres’ support consultants provide the non-medical formal care. The various types of support provided by PATIO and IntermeZZo overlap, although IntermeZZo offers a more extensive range of informal care compared with PATIO and PATIO offers additional types of non-medical

formal care: music therapy and art therapy. These therapies are offered to both oncology inpatients of the Erasmus MC Cancer Institute and PATIO’s visitors. See [box 1](#) for further information regarding centres for information and support, and their services.

Data collection

Socioeconomic demographics

Information of the centres’ visitors collected included gender, age, whether they considered themselves a patient or a relative/caregiver/friend and the number of visits to PATIO/IntermeZZo. In case visitors considered themselves a patient, additional information was collected regarding their self-reported diagnosis, whether they received active treatment, and if so, the duration of their treatment period. Sociodemographic information of the patients treated at the hospitals included gender, age, their self-reported diagnosis and the duration of their treatment period.

Visitors’ experiences and patients’ interest

To produce an understanding of the expectations and needs of centres’ visitors and patients treated at the hospital, an interview guide was developed prior to starting the interviews. The interview guide was developed by the members of the research team, with backgrounds in nursing, psychology, oncology and health sciences. Questions with set response options and space for elaboration were used (see [tables 1 and 2](#)). The interviews conducted at PATIO/IntermeZZo focused on the reasons for visiting the centres, whether these visits had fulfilled their expectations and needs for supportive care, and whether they had any points of improvements regarding the care provided by the centres. The semistructured interviews conducted among the patients treated at the affiliated hospitals, during the same periods in time, focused on whether they knew PATIO/IntermeZZo and whether they intended to visit PATIO/IntermeZZo.

Box 1 The (services of) centres for information and support in the Netherlands

In the Netherlands, Institutions for Psychosocial Oncology (IPSO) centres provide easily accessible psychosocial support to individuals affected by cancer.¹⁵ There are 81 IPSO centres in the Netherlands, each having at least one paid coordinator/manager and several trained volunteers. Currently, the Dutch Cancer Society (KWF Kankerbestrijding) provides funding for one paid coordinator/manager position at each centre.¹⁹ Most centres operate as independent Public Benefit Organizations (ANBIs); in a limited number of cases, the centres are affiliated with a (university) hospital.

In most centres, psychosocial support primarily comprises various forms of informal care. The specific services offered may vary between centres. Examples are as follows:

- ⇒ Facilitated gatherings to meet peers, relatives and bereaved ones.
- ⇒ Workshops, for example, yoga, tai chi, drawing workshops, cosmetic course 'look good, feel better'.
- ⇒ Information sessions organised by volunteers or patient organisations, for example, how to deal with taste adjustments, stress and return-to-work information.
- ⇒ Individual treatments, for example, massage.
- ⇒ Practical and emotional support by volunteers.

A small number of IPSO centres offer non-medical formal care, in addition to the informal services they offer. Examples are as follows:

- ⇒ The care provided by support consultants
 - ⇒ Support consultants are trained healthcare professionals with a bachelor's degree, such as nurses, physical therapists and social workers, with at least 5 years of work experience within the domain of oncology. They are trained through an accredited training.²⁰ The information and advice support consultants provide depend on the patient's specific needs and aims to enhance various aspects such as coping skills, sexuality, work, well-being, access to healthcare services and maintaining continuity of care.¹¹ Further, they help patients find reputable sources of information. In case targeted referral to medical care is indicated, the support consultants assist the patient in this referral process as they cooperate with healthcare providers.
- ⇒ Art therapy and music therapy
 - ⇒ Therapies provided by professionals with a bachelor's degree.

In our study, we categorised centres offering both informal care and non-medical formal care as 'centres for information and support'. The centres' managers, support consultants, music therapists and art therapists closely collaborate with healthcare professionals working at the hospital. Patients can be referred to the centres' non-medical formal care services, by the hospitals' healthcare providers, for example, oncologists, nurses and social workers.

Data analyses

Descriptive statistics were calculated for frequencies, means, medians and ranges of the visitors' and patients' characteristics. Multilevel analyses, using Fisher-Freeman-Halton Exact tests, were used to

analyse the differences over time, between the centres and the affiliated hospitals. A two-sided significance level of $p < 0.05$ was considered as statistically significant. All statistical analyses were performed with help of the Statistical Package for the Social Sciences V.29 (SPSS; <http://www.spss.com>). Further, thematic analysis was used to gain insight into the visitors' and patients' experiences: any elaborations provided by visitors and patients in response to the questions were transcribed verbatim. Further, question 3, directed to visitors, was an open question which was also transcribed verbatim. We used open and axial coding to analyse the answers of question 3 and the elaborations of respondents to questions 4 and 5, directed to visitors, and questions 2B, 3 and 4, directed to patients. Elaborations of responses of visitors and patients were used as supportive information

RESULTS

Results of the interviews

572 participants were interviewed for this study (183 at T0, 197 at T1 and 192 at T2). The results of the interviews conducted at PATIO and IntermeZZo are presented first (table 1), followed by the results of the interviews conducted at the hospitals (table 2).

Visitors of PATIO and IntermeZZo

111 and 123 visitors were interviewed at PATIO and IntermeZZo, respectively. The majority of all visitors of PATIO were female (62%) and around 80% of PATIO's visitors were patients. The same holds for IntermeZZo's visitors: 83% were female and almost 85% were patients. Most patients were either in an active treatment phase or follow-up after cancer treatment in the period the interviews took place. Table 1 provides an overview of visitor demographics and their answers to the interview questions, during three different periods in total and over time.

The way visitors learnt about the centres differed significantly ($p < 0.001$). Overall, visitors primarily learnt about IntermeZZo via healthcare providers (48.8%), followed by family members and friends (23.6%). At PATIO, answers corresponding to the category 'Other' were mentioned most often (39.6%), for example, walking past PATIO on their way to the Erasmus MC Cancer Institute (34.1%), and learning about PATIO via volunteers, music and art therapists, and support consultants providing support at the inpatient clinic (29.5%). The way visitors learnt about PATIO significantly changed over time: less visitors learnt about PATIO via banners, flyers or posters at T1 compared with T0 and T2 ($p < 0.03$). The way visitors learnt about IntermeZZo did not significantly change over time.

Reasons to visit PATIO and IntermeZZo

Most visitors visited PATIO and IntermeZZo to relax (91.9% and 94.3%), to receive the support

Table 1 Demographics and answers provided by visitors of PATIO and Intermezzo during three different periods over time (T0, T1 and T2)

	Measurement T0			Measurement T1			Measurement T2			Total	
	PATIO	Intermezzo		PATIO	Intermezzo		PATIO	Intermezzo		PATIO	Intermezzo
Visitors (n)	39	40		36	48		36	35		111	123
Patients (active treatment or follow-up phase)	34 (31)	34 (33)		31 (16)	39 (22)		23 (21)	31 (27)		88 (82)	104 (82)
Relative/friend/acquaintances	4	6		5	9		13	4		22	19
Other	1	0		0	0		0	0		1	0
Female:male (n)	30:9	32:8		19:17	39:9		20:16	31:4		69:42	102:21
Mean age (Years (min.-max.))	57.7 (26-77)	57.8 (21-78)		54.0 (24-77)	58.0 (28-82)		59.6 (30-75)	58.6 (41-75)		57.1 (24-77)	58.1 (21-82)
Median number of visits (Min.-max.)	4 (0-50)	12 (1-150)		9 (0-60)	6 (1-400)		3 (0-60)	18 (3-500)		4 (0-60)	10 (1-500)
Questions interview											
1. How did you get to know PATIO/Intermezzo? (n (valid %))											
Banners, flyers or posters	10 (25.6)	2 (5.0)		6 (16.7)	2 (4.2)		16 (44.4)	3 (8.6)		32 (28.8)	7 (5.7)
Healthcare provider(s)	6 (15.4)	18 (45.0)		11 (30.6)	26 (54.3)		8 (22.2)	16 (45.6)		25 (22.5)	60 (48.8)
Family members or friends	4 (10.3)	13 (32.5)		5 (13.9)	8 (16.7)		1 (2.8)	8 (22.9)		10 (9.0)	29 (23.6)
Other	19 (48.7)	7 (17.5)		14 (38.9)	12 (25.0)		11 (30.6)	8 (22.9)		44 (39.6)	27 (22.0)
Missing	-	-		-	-		-	-		-	-
2. What are the reasons you visited PATIO/Intermezzo? (n (valid %))											
First visit: exploring the centres offer	6 (15.4)	2 (5.0)		2 (5.6)	1 (2.1)		11 (30.6)	0 (0.0)		19 (17.1)	3 (2.4)
Support/information/advice support consultant	21 (53.8)	19 (47.5)		22 (61.1)	29 (60.4)		14 (38.9)	23 (65.7)		57 (51.4)	71 (57.7)
Relaxation	35 (89.7)	38 (95.0)		32 (88.9)	43 (89.6)		35 (97.2)	35 (100.0)		102 (91.9)	116 (94.3)
Meeting peers	12 (30.8)	20 (50.0)		7 (19.4)	11 (22.9)		12 (33.3)	24 (68.6)		31 (27.9)	55 (44.7)
Music/art therapy	11 (28.2)	-		16 (44.4)	-		3 (8.3)	-		30 (27.0)	-
Other	1 (2.6)	1 (2.5)		0 (0.0)	2 (4.2)		0 (0.0)	0 (0.0)		1 (0.9)	3 (2.4)
Missing	-	-		-	-		-	-		-	-
3. What distinguishes PATIO/Intermezzo from a general community centre? (open question) identified reasons: (n (valid %))											
Focused on cancer	12 (52.2)	23 (57.5)		22 (61.1)	34 (70.8)		21 (58.3)	25 (71.4)		55 (57.9)	82 (66.7)
Expertise support consultants	10 (43.5)	7 (17.5)		4 (11.1)	2 (4.2)		6 (16.7)	1 (2.9)		20 (21.1)	10 (8.1)
Peers	4 (17.4)	13 (32.5)		8 (22.2)	26 (54.2)		11 (30.6)	16 (45.7)		23 (24.2)	55 (44.7)
Affiliated to hospital	5 (21.0)	-		4 (11.1)	1 (2.1)		5 (13.9)	-		14 (14.7)	1 (0.8)
Easily accessible and relaxing atmosphere	12 (52.2)	12 (30.0)		8 (22.2)	6 (12.5)		1 (2.8)	2 (5.7)		21 (22.1)	20 (16.2)
Trained employees and volunteers	7 (30.4)	18 (45.0)		5 (13.9)	9 (18.8)		5 (13.9)	8 (22.9)		17 (17.9)	35 (28.5)
Offer workshops	2 (8.7)	10 (25.0)		1 (2.8)	2 (4.2)		0 (0.0)	1 (2.9)		3 (3.2)	13 (10.6)
I do not know	0 (0.0)	-		4 (11.1)	-		2 (5.6)	-		6 (6.3)	-

Continued

	Measurement T0		Measurement T1		Measurement T2		Total	
	PATIO	IntermeZZo	PATIO	IntermeZZo	PATIO	IntermeZZo	PATIO	IntermeZZo
Being away from hospital	2 (8.7)	–	–	–	–	–	2 (2.1)	–
Better protected against COVID compared with waiting inside the hospital	–	–	2 (5.6)	–	–	–	2 (2.1)	–
Missing	–	–	–	–	–	–	–	–
4. Did the visit(s) meet your expectations and needs? (n (valid %))								
Yes	38 (97.4)	40 (100.0)	35 (97.2)	48 (100.0)	36 (100)	35 (100.0)	109 (98.2)	123 (100)
Somewhat	1 (2.6)	0 (0)	1 (2.8)	0 (0)	0 (0.0)	0 (0)	2 (1.8)	0 (0)
No	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0)	0 (0)
Missing	–	–	–	–	–	–	–	–
5. Are there any improvements for PATIO/IntermeZZo? (n (valid %))								
Yes	6 (25.0)	12 (30.0)	15 (41.7)	21 (43.8)	7 (19.4)	13 (37.1)	28 (29.2)	46 (37.4)
No	12 (50.0)	21 (52.5)	17 (47.2)	21 (43.8)	17 (47.2)	20 (57.2)	46 (47.9)	62 (50.4)
I don't have sufficient experience	5 (20.8)	6 (15.0)	4 (11.1)	5 (10.3)	12 (33.3)	2 (5.7)	20 (20.8)	13 (10.6)
I don't know	1 (4.2)	1 (2.5)	0 (0)	1 (2.1)	0 (0)	0 (0)	2 (2.1)	2 (1.6)
Missing	–	–	–	–	–	–	–	–
PATIO, Patient Information Center Oncology.								

Table 1 Continued

Table 2 Demographics and answers provided by oncology patients treated at the Erasmus MC Cancer Institute and Isala Oncology Center, during three different periods over time (T0, T1 and T2)

	Measurement T0		Measurement T1		Measurement T2		Total	
	Erasmus MC Cancer Institute	Isala	Erasmus MC Cancer Institute	Isala	Erasmus MC Cancer Institute	Isala	Outpatient clinic	Erasmus MC Cancer Institute
Patients (n)	52	52	58	55	39	42	40	189
Active phase treatment	52	52	58	55	39	42	13	172
Follow-up after curative therapy	–	–	–	–	–	–	7	7
Palliative phase disease trajectory	–	–	–	–	–	–	10	10
Female:male (n)	27:25	37:15	30:28	32:23	19:20	22:20	16:24	92:97
Mean age (years (min.–max.))	61 (19–82)	60 (36–78)	58 (20–80)	65 (22–86)	63 (34–80)	65 (32–85)	62 (28–78)	61 (19–82)
Median number of visits (min.–max.)	0 (0–2)	0 (0–100)	0 (0–2)	0 (0–6)	0 (0–50)	0 (0–1)	0 (0–3)	0 (0–50)
1. Are you familiar with PATIO/Intermezzo? (n (valid %))								
Yes	20 (38.5)	27 (51.9)	21 (36.2)	20 (36.4)	11 (28.2)	12 (28.6)	16 (40.0)	68 (36.0)
Somewhat	18 (34.6)	3 (5.8)	8 (13.8)	3 (5.5)	9 (23.1)	3 (7.1)	8 (20.0)	43 (22.8)
No	14 (26.9)	22 (42.3)	29 (50.0)	32 (58.2)	19 (48.7)	27 (64.3)	16 (40.0)	78 (41.3)
Missing	–	–	–	–	–	–	–	–
1A. How did you learn about PATIO/Intermezzo? (n (valid %))	n=38	n=30	n=29	n=23	n=20	n=15	n=24	n=111
Banners, flyers or posters	30 (78.9)	6 (20.0)	4 (13.8)	2 (8.7)	9 (45.0)	1 (6.7)	9 (37.5)	52 (46.8)
Healthcare provider(s)	3 (7.9)	18 (60.0)	16 (55.2)	9 (39.1)	5 (25.0)	10 (66.7)	13 (54.2)	37 (33.3)
Family members or friends	1 (2.6)	2 (6.7)	0 (0.0)	3 (13.0)	1 (5.0)	1 (6.7)	0 (0.0)	2 (1.8)
Other	4 (10.5)	3 (10.0)	8 (27.6)	6 (26.1)	5 (25.0)	2 (13.3)	2 (8.3)	19 (17.1)
I don't know	0 (0.0)	1 (3.3)	1 (3.4)	3 (13.0)	0 (0.0)	1 (6.7)	0 (0.0)	1 (0.9)
Missing	14	22	29	32	19	27	16	78
1B. What are the reasons you visited PATIO/Intermezzo? (n (valid %))	n=9	n=5	n=4	n=4	n=5	n=1	n=5	n=23
First visit: exploring the centre's offer	6 (66.7)	2 (40.0)	2 (50.0)	2 (50.0)	2 (40.0)	1 (100.0)	3 (60.0)	13 (56.5)
Support/information/advice support consultant	1 (11.1)	4 (80.0)	0 (0.0)	1 (25.0)	3 (60.0)	1 (100.0)	1 (20.0)	5 (21.7)
Music/art therapy	1 (11.1)	–	0 (0.0)	–	1 (20.0)	–	1 (20.0)	3 (13.0)
Relaxation	6 (66.7)	2 (40.0)	4 (100)	3 (75.0)	4 (80.0)	0 (0.0)	2 (40.0)	16 (69.6)
Meeting peers	0 (0.0)	2 (40.0)	0 (0.0)	0 (0.0)	1 (20.0)	0 (0.0)	1 (20.0)	2 (8.7)
Other	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)
Missing	43	47	54	51	34	41	35	166
2A. What is the reason you have not visited PATIO/Intermezzo (yet)? (n (valid %))	n=43	n=47	n=54	n=51	n=34	n=41	n=35	n=166
I do not know it	14 (32.6)	23 (48.9)	29 (53.7)	32 (62.7)	19 (55.9)	27 (65.9)	16 (45.7)	78 (47.0)

Continued

Table 2 Continued

	Measurement T0		Measurement T1		Measurement T2		Total		
	Erasmus MC Cancer Institute	Isala	Erasmus MC Cancer Institute	Isala	Erasmus MC Cancer Institute	Isala	Outpatient clinic	Erasmus MC Cancer Institute	Isala
I don't know what the centre can offer me	11 (25.6)	3 (6.4)	3 (5.6)	3 (5.9)	8 (23.5)	3 (7.3)	7 (20.0)	29 (17.5)	9 (6.5)
I can't combine it with my appointments	5 (11.6)	2 (4.3)	2 (3.7)	0 (0)	0 (0)	1 (2.4)	2 (5.7)	9 (5.4)	3 (2.2)
I do not feel the need	9 (20.9)	10 (21.3)	14 (25.9)	6 (11.8)	6 (17.6)	5 (12.2)	5 (14.3)	34 (20.5)	21 (15.1)
I already receive psychosocial care	0 (0.0)	0 (0.0)	1 (1.9)	0 (0.0)	0 (0.0)	0 (0.0)	0 (0.0)	1 (0.6)	0 (0.0)
Other	4 (9.3)	9 (17.3)	5 (9.3)	10 (19.6)	1 (2.9)	(12.2)	5 (14.3)	15 (9.0)	24 (17.3)
Missing		5	4	4	5	1	5	23	10
2B. Do you think you will visit PATIO/Intermezzo in the future?	n=43	n=47	n=54	n=51	n=34	n=41	n=35	n=166	n=139
Yes	11 (25.6)	7 (14.9)	10 (18.5)	14 (27.5)	5 (14.7)	6 (14.6)	5 (14.3)	31 (18.7)	27 (19.4)
May be	11 (25.6)	14 (29.8)	18 (33.3)	12 (23.5)	11 (32.4)	12 (29.3)	9 (25.7)	49 (29.5)	38 (27.3)
No	21 (48.8)	26 (55.3)	26 (48.1)	25 (49.0)	18 (52.9)	23 (56.1)	20 (60.0)	86 (51.8)	74 (53.2)
Missing	9	5	4	4	5	1	5	23	10
3. Did you feel the need for PATIO's offer during the treatment process? (Extra question outpatient clinic)									
Yes	–	–	–	–	–	–	10 (28.6)	10 (28.6)	–
I don't know	–	–	–	–	–	–	3 (8.6)	3 (8.6)	–
No	–	–	–	–	–	–	22 (62.9)	22 (62.9)	–
Missing	–	–	–	–	–	–	–	154	–
4. Would it be of added value if an initiative like PATIO/Intermezzo was an integral part of the treatment process?									
Yes	39 (75.0)	47 (90.4)	55 (94.8)	55 (0.0)	35 (89.7)	38 (90.5)	34 (85.0)	163 (86.2)	140 (94.0)
May be	9 (17.3)	5 (9.6)	3 (5.2)	0 (0.0)	3 (7.7)	3 (7.1)	5 (12.5)	20 (10.6)	8 (5.4)
No	4 (7.7)	0 (0.0)	0 (0.0)	0 (0.0)	1 (2.6)	1 (2.4)	1 (2.5)	5 (2.6)	1 (0.7)
Missing	–	–	–	–	–	–	–	–	–

PATIO, Patient Information Center Oncology.

consultants' care (51.4% and 57.7%), and to meet peers (27.9% and 44.7%). Additionally, 27.0% of visitors visited PATIO to receive care provided by a music or art therapist (table 1). Significantly, more visits to IntermeZZo were made in order to meet peers compared with PATIO ($p < 0.006$). The proportion of the reasons to visit the centres changed little between the measurements. There were no relevant differences found between male and female visitors and patients and relatives.

My partner and I really wanted some advice on how to cope with cancer. I had some questions regarding how you can 'brace' yourself against the impact of cancer and its consequences on the daily life. When I was diagnosed with cancer I assumed the worst thing in life has happened to me and the support consultant helped me put that into perspective [through their advice].

Quote visitor of PATIO, male, early 50's

Appreciation from visitors of PATIO and IntermeZZo

Almost all visitors of PATIO (98.2%) and IntermeZZo (100%) reported that their visit fulfilled their expectations and needs because of, among other things, the support consultants' professional advice, the relaxed atmosphere, the offer of workshops and the volunteers' support. For example, one participant said:

I was very lonely in the recent years and I experience a lot of benefits from IntermeZZo as you can discuss a wide range of issues with the support consultant and IntermeZZo is very approachable. The care they provide is heartwarming, the staff knows me and everyone is very friendly. There is a very open and relaxed atmosphere and you can have nice conversations with peers and employees. I even hand out flyers of IntermeZZo to other patients so that they can have a look.

Quote visitor of IntermeZZo, female, early 50's

Visitors distinguished the centres from general community centres, which are 'a building or other facility providing social, recreational and educational facilities for a community'.¹⁴ See the quotations below for illustration. The central theme at both PATIO (57.9%) and IntermeZZo (66.7%) was that the centres had expertise on cancer-related topics. The possibility to meet peers was also often mentioned at IntermeZZo (44.7%) while that was less often mentioned at PATIO (24.2%) (see table 1).

'PATIO is connected to the hospital and the support consultants have knowledge and experience within the field of oncology and at a general community center they do not have this expertise. There is a different cordiality at PATIO as they know that every visitor experiences misery in their life and they respond well to that.

Quote visitor of PATIO, female, mid 40's

I strongly feel that volunteers are trained because they ask the right questions and sometimes they talk from their own experiences. You have much more of a conversation here and you feel heard about your disease process, after all that is what I come here for. You will not find that outside, if I would go to a general community center I would be a random individual and here I am a peer. The services here are focused on the disease process.

Quote visitor of IntermeZZo, female, mid 40's

Suggestions for improvement

Almost one-third of all PATIO's visitors (29.2%) and 37.4% of IntermeZZo's visitors had some suggestions to improve the centres' offer. The suggestions mainly included creating awareness of the centres, improving the referral to the centres by healthcare professionals, and the offer of workshops. General suggestions were also mentioned, for example, signposting. One interviewee said:

More awareness regarding the existence of PATIO needs to be created among patients, preferably by the oncologist. I believe there is a lot of demand for this type of care among oncology patients. Yet, the oncologist did not bring up PATIO.

Quote visitor of PATIO, female, late 40's

Implemented actions

Between measurements, the study group and the centres' employees, including managers and support consultants, carried out various actions: consultations took place with, and presentations were provided to, healthcare professionals and stakeholders of the affiliated hospitals, aimed to enhance the referral to PATIO and IntermeZZo. These professionals and stakeholders included oncologists, nurses, members of the oncology psychosocial care, the hospitals' advisory board and research groups. The support consultants provided clinical classes for nurses and medical students at the hospitals. Further, several actions were carried out to increase the awareness of the centres among potential visitors: the centres' activities and workshops were shared on social media and their websites, monthly newsletters were sent out, (renewed) flyers and banners were circulated in the hospitals' waiting rooms and volunteers visited inpatients of the hospitals to promote the centres' services. Furthermore, during holidays, small promotional gifts were handed out to oncology inpatients at the Erasmus MC Cancer Institute. Workshops were resumed at both centres after the COVID-19 lockdowns ended and the number of workshops was expanded. Lastly, both centres participated in a national Institutions for Psychosocial Oncology working group, focusing on quality assurance and improvement.¹⁵

Patients with cancer treated at the hospitals

189 and 149 patients were interviewed at the Erasmus MC Cancer Institute and the Isala Oncology Center, respectively. Table 2 provides an overview of the

patients' demographics and the answers they provided, during three different periods over time and in total.

Awareness of centres among patients with cancer

At the Erasmus MC Cancer Institute, 58.7% of interviewed patients were aware of PATIO's existence, of which 22.8% recognised its name but were unfamiliar with what PATIO offered. At the Isala Oncology Center, 45.1% of all interviewed patients were aware of the IntermeZZo's existence, of which 6.1% only recognised its name (see [table 2](#)). This did not significantly change over time.

The way patients learnt about the centres differed significantly between hospitals ($p < 0.05$). Most patients learnt about PATIO via banners, flyers or posters (46.8%), whereas most patients learnt about IntermeZZo via healthcare providers (54.4%).

Significant changes were observed in how patients learnt about PATIO over time: fewer patients learnt about PATIO via banners, flyers or posters at T1. This was most likely due to the removal of banners inside the hospital during the COVID-19 lockdowns during which PATIO was closed ($p < 0.001$).

Reasons PATIO and IntermeZZo were not (yet) visited

Patients who did not visit PATIO or IntermeZZo stated that they did not know the centres (47.0% and 59.0%) or that they did not feel the need to visit the centres (20.5% and 15.1%). Additionally, 18.1% of all patients who did not visit PATIO stated that they did not know what the centre could offer; 17.5% of all patients at the Isala Oncology Center gave other reasons, including that they were not physically fit enough to visit IntermeZZo or that they were dependent of others in terms of transportation.

The patients' need for PATIO and IntermeZZo

Patients who had not yet visited the centres received information regarding the centres' services. They were then asked whether they felt the need to visit the centres in the future; 18.7% of patients at the Erasmus MC Cancer Institute and 19.4% of patients at the Isala Oncology Center indicated that they would definitely visit the respective centres in the future. Patients mentioned multiple reasons for a visit, which included: 'to relax' at PATIO (51.6%) and IntermeZZo (59.3%), to receive care from support consultants at PATIO (38.7%) and IntermeZZo (29.6%), to meet peers at PATIO (19.4%) and IntermeZZo (18.5%), and to explore the services of PATIO (29.0%) and IntermeZZo (14.8%). Further, 29.5% of patients at the Erasmus MC Cancer Institute and 27.3% of patients at the Isala Oncology Center expressed a possible interest in visiting the centres, and 51.8% of patients at the Erasmus MC Cancer Institute and 53.2% of patients at the Isala Oncology Center indicated that they did not feel such need. Reasons provided were that patients experienced sufficient support, lack of questions or

problems and that they liked doing their own hobbies to find distraction. The desire to visit PATIO/IntermeZZo remained consistent over time. Lastly, 28.6% of the patients interviewed during a different phase of their disease stated that they felt the need to visit PATIO in retrospect, and 17.1% of these patients stated that they would definitely visit PATIO in the future, 25.7% would possibly visit PATIO.

The majority of patients interviewed at the Erasmus MC Cancer Institute (86.2%) and the Isala Oncology Center (94.0%) believed it would be beneficial if PATIO/IntermeZZo were integrated into the treatment process. For example, two patients said:

'It is valuable if people dealing with cancer know about it [IntermeZZo]. The phase in your life of being ill brings new and unexpected things that you had not thought about yourself and I believe IntermeZZo is a place where you can discuss such things. Moreover, you can meet other people who are going through the same phase.

Patient treated at the Isala Oncology Center, female, mid 60's

It's always a good thing to mention it [PATIO] because it lowers the threshold to visit and it can always complement to the care that is provided by the medical staff. Everybody deals with the disease differently and for some, such care is very valuable.

Patient treated at the Erasmus MC Cancer Institute, male, early 70's

DISCUSSION

This study aimed to investigate: (1) to what extent PATIO and IntermeZZo, centres for information and support, meet the needs of its visitors, that is, patients, family members and friends and (2) the interest for these centres among 'non-visitors' with cancer treated at the affiliated hospitals. Reasons most frequently mentioned to visit the centres were to relax (93.1%), to seek professional advice (54.6%) and to meet peers (36.3%). Moreover, 27.0% of visitors visited PATIO to receive care provided by a music therapist or an art therapist. The visits met the expectations and needs of almost all visitors (99.1%).

The ranking of reasons to visit the centres overlapped and the main reason to visit both centres was 'to relax'. Of note, it should be mentioned that the centres have different locations in relation to the hospitals and a distinctive availability of space to offer their services, which may induce differences in the 'function' of the centres. Responses classified within the extensive central theme 'to relax' could vary from waiting between appointments, mainly mentioned at PATIO, to participating in workshops, mainly mentioned at IntermeZZo.

The centres' non-medical formal services, offered by support consultants, and PATIO's music therapist and art therapist, were also frequently mentioned as

reason for visiting the centres and why the visits had met the visitors' needs. This is in line with two recently published Dutch studies focused on evaluating the care delivered by support consultants^{16 17}: one study concerned a randomised controlled trial in which patients were assigned to either care as usual or care as usual plus consultations with a support consultant. The study found no significant differences between the intervention (n=42) and control group (n=47) in quality of life but did find that participants who consulted the consultant seemed to have higher levels of self-efficacy and satisfaction, and made less use of supportive care services.¹⁶

Our findings suggest that IntermeZZo has been better embedded in the care pathway of patients treated at the Isala Oncology Center as the healthcare professionals were more likely to alert patients about IntermeZZo than healthcare professionals of the Erasmus MC Cancer Institute about PATIO. A possible explanation is that IntermeZZo has existed longer compared with PATIO and, thus, there is a greater chance that healthcare professionals are aware of its services. It can also be hypothesised that there are shorter communication lines between healthcare providers of the Isala Oncology Center and IntermeZZo as it is a regional hospital, which may make it easier to embed IntermeZZo in the care pathway. Considerably more doctors are employed at university hospitals and there is a higher turnover of junior doctors, thereby hindering effective communication between different healthcare providers and making it challenging to embed PATIO in the cancer-specific pathways of the Erasmus MC Cancer Institute.

The added value of such centres is complex to demonstrate as one cannot expect improvements in terms of the disease, for example, prognosis, by visiting such centres. Yet, previous research has shown the added value of these centres in order to deal with cancer among 'users'.⁹ The current study supports the evidence from previous research as the visitors' needs are met by the centres' services. In addition, the Dutch Government recently published the Integral Care Agreement, a health policy aiming to keep the care provided in the Netherlands affordable and accessible in the future. In which the Dutch government emphasises the added value of informal care and stated the following: 'Appropriate care starts with self-care and informal care, and only when this contributes insufficiently to the care needs, formal care is in line'.¹⁸ Centres for information and support operationalise that policy by providing informal care and non-medical formal care, and serving as a link to medical formal care.

As previously mentioned, a group of patients and their relatives feel a need for information on matters not restricted to medical care and support. Based on our results, we conclude that these needs can potentially be met through the services of centres for information and

support: visitors were satisfied with the services provided, including the provision of non-medical information and emotional support, and 90% of patients indicated that it would be beneficial if PATIO/IntermeZZo would be an integral part of the treatment. Consequently, services of centres for information and support may be an effective strategy to meet the needs of patients and their relatives. This is especially urgent given increasing healthcare costs and budget strains. Future research could explore how such centres can best be integrated into the specific context of the Dutch healthcare system. Furthermore, examining the potential applicability of these centres in other countries warrants exploration, to provide insight into whether and how they may fit different healthcare systems.

Strengths and limitations

The design of our study not only allowed us to evaluate the needs and expectations of the centres' visitors regarding the centres' services but also allowed us to directly implement the visitors' suggestions to improve the centres' services. In addition, it was possible to re-evaluate the results of the undertaken actions and even further adjust the implementations. This is particularly of importance when examining the usefulness and benefits of centres for information and support: such centres can only succeed, and add value in reducing demand on formal medical care, when these centres meet the expectations and needs of its visitors. Further, our study is the first to explore the awareness and interest for this type of support among 'non-users'. Our results indicate that around one-fifth of all patients with cancer appreciate this type of care, and that nearly all patients with cancer consider such centres to be of added value to formal care.

Unfortunately, due to the pandemic measures, it was not allowed to accompany patients to the appointments at the hospitals' the outpatient treatment departments, and thus, it was not possible to additionally interview their companions, nor was it possible to request their contact information, given that the data were collected anonymously. Hence, questions regarding the relatives' interest and need for this type of support remain unanswered in this study. Lastly, the measurements occurred between COVID-19 lockdowns, therefore, the actions performed, aimed at promoting the centres, may have had less positive impact on creating awareness of the centres among the hospitals' healthcare providers, oncology patients and different stakeholders, for example, general practitioners. PATIO and IntermeZZo had to close their doors several times and both centres had only been able to offer their care to a limited extent, which also may have stagnated growth in awareness and stagnation in the development (and improvement) of its services.

CONCLUSIONS

This study expands our understanding of the ways to address the needs of oncology patients and their relatives, taking into account the increasing demand for, and costs of, formal care in the future. Oncology patients consider the centres important initiatives and believe they should be integrated into the treatment process. Centres for information and support meet the needs for support of a group of patients with cancer and their relatives, with nearly 100% stating that the visits met their expectations and needs. Continuously creating awareness among healthcare providers is necessary to ensure that oncology patients and their relatives, who feel the need for such support, can profit from these services.

Contributors HPAD: conceptualisation, data curation, methodology, formal analysis, investigation, writing—original draft, project administration, visualisation, JJVB: conceptualisation, methodology, validation, formal analysis, writing—review and editing, CCDvdR: conceptualisation, writing—review and editing, EJE: conceptualisation, validation, writing—review and editing, funding acquisition, GMRMP: conceptualisation, writing—review and editing, CjH: conceptualisation, writing—review and editing, LWK: conceptualisation, methodology, validation, formal analysis, investigation, writing—review and editing, supervision, guarantor.

Funding The research was supported by a grant from the Roparun Foundation.

Disclaimer There was no involvement in study design, in the collection, analysis and interpretation of data, in the writing of the articles, and in the decision to submit it for publication.

Competing interests None declared.

Patient consent for publication Not applicable.

Ethics approval This study involves human participants but The Medical Ethical Committee of the Erasmus Medical Center in Rotterdam reviewed and granted exemption from ethical review for this study, according to the Dutch Medical Research Involving Human Subjects Act (WMO) (MEC-2020-0569).

Provenance and peer review Not commissioned; externally peer reviewed.

Data availability statement Data are available on reasonable request. All data relevant to the study are included in the article or uploaded as online supplemental information. All data relevant to the study are included in the article, data are available on reasonable request.

Open access This is an open access article distributed in accordance with the Creative Commons Attribution Non Commercial (CC BY-NC 4.0) license, which permits others to distribute, remix, adapt, build upon this work non-commercially, and license their derivative works on different terms, provided the original work is properly cited, appropriate credit is given, any changes made indicated, and the use is non-commercial. See: <http://creativecommons.org/licenses/by-nc/4.0/>.

ORCID iD

Helen P A Driessen <http://orcid.org/0000-0001-8521-5980>

REFERENCES

- 1 Nederlandse Federatie van Kankerpatiënten organisaties (NFK). Goede Kankerzorg is Meer Dan Een Medische Behandeling. 2018. Available: <https://nfk.nl/onderzoeken/goede-kankerzorg-is-meer-dan-een-medische-behandeling>
- 2 Leonidou C, Giannousi Z. Experiences of caregivers of patients with metastatic cancer: what can we learn from them to better support them. *Eur J Oncol Nurs* 2018;32:25–32.
- 3 Kim H, Yi M. Unmet needs and quality of life of family caregivers of cancer patients in South Korea. *Asia Pac J Oncol Nurs* 2015;2:152–9.
- 4 van Roij J, Raijmakers N, Ham L, et al. Quality of life and quality of care as experienced by patients with advanced cancer and their relatives: a multicentre observational cohort study (eQuiPe). *Eur J Cancer* 2022;165:125–35.
- 5 Lambert SD, Girgis A. Unmet supportive care needs among informal caregivers of patients with cancer: opportunities and challenges in informing the development of interventions. *Asia Pac J Oncol Nurs* 2017;4:136–9.
- 6 Nederlandse Federatie van Kankerpatiënten organisaties (NFK). Iemand Dicht Bij je met Kanker, hoe is of was dat Voor Jou? 2023. Available: <https://nfk.nl/nieuws/ruim-de-helft-van-naasten-van-mensen-met-kanker-past-leven-helemaal-aan>
- 7 Driessen HPA, Busschbach JJV, van der Rijt CCD, et al. Unmet care needs of patients with advanced cancer and their relatives: multicentre observational study. *BMJ Support Palliat Care* 2023:spcare–2023
- 8 IKNL. Verwijsgids kanker, zorgaanbieder, ondersteuningsconsulent. 2023. Available: <https://www.verwijsgidskanker.nl/zorgaanbieder/76/ondersteuningsconsulent>
- 9 Driessen HPA, Kranenburg LW, van der Rijt KCD, et al. Evaluation of centers for information and support combining formal and informal care for patients with cancer: a systematic review of the literature. *Support Care Cancer* 2022;30:7079–98.
- 10 Edgar L, Remmer J, Rosberger Z, et al. An oncology volunteer support organization: the benefits and fit within the health care system. *PSYCHO-ONCOLOGY* 1996;5:331–41.
- 11 Jones M, Pietilä I. Expertise, advocacy and activism: a qualitative study on the activities of prostate cancer peer support workers. *Health (London)* 2020;24:21–37.
- 12 Wetzel JW, Wallace NE. *United Nations and its agencies*. 2015.
- 13 Delmas PM, Giles RL. *Qualitative research approaches and their application in education*. 2023.
- 14 Oxford English Dictionary. *Community centre*. Oxford University Press, 2023.
- 15 IPSO - Institutions for Psychosocial Oncology. Ons verhaal. 2024. Available: <https://ipso.nl/over-ipso/over-verhaal>
- 16 Berezowska A, Passchier E, Bleiker E. Professional patient navigation in a hospital setting: a randomized controlled trial. *Support Care Cancer* 2021;29:2111–23.
- 17 Berezowska A, Passchier E, Bleiker E. Evaluating a professional patient navigation intervention in a supportive care setting. *Support Care Cancer* 2019;27:3281–90.
- 18 Ministerie van Volksgezondheid Welzijn en Sport. *Integraal Zorgakkoord: Samen werken aan gezonde zorg*. 2022.
- 19 KWF Kankerbestrijding. KWF Investeert 16 Miljoen in Centra Voor Mensen met Kanker. 2022. Available: <https://www.kwf.nl/nieuws/kwf-investeert-16-miljoen-in-centra-voor-mensen-met-kanker>
- 20 Stichting OOK (Stichting Optimale Ondersteuning bij Kanker). Opleiding Ondersteuningsconsulent. 2024. Available: <https://www.stichting-ook.nl/opleiding-ondersteuningsconsulent/#modules>