Patient Empowerment Among People Attending Cancer Follow-Up – Results from a Nationwide Questionnaire Survey

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Abstract

Purpose

To investigate levels of empowerment, possibilities for empowerment and perceived importance of empowerment among Danes in cancer follow-up.

Methods

From nation-wide registers a randomly selected group of people diagnosed with one of ten different cancer diagnoses between one and five years ago were invited to complete the newly developed ‘Cancer Patient Empowerment Questionnaire’ (CPEQ). Respondents who reported that they were in a follow-up program were included in the analysis. Frequencies of answers to the items in the questionnaire were calculated.

Results

In total, 1,418 people with a diagnosis of cancer returned the questionnaire (response rate 54%). Of these, 1,042 reported being in follow-up and were included in the analysis. Most respondents experienced that there was a plan for their follow-up (83%) and felt at ease with both the frequency (80%) and content of the follow-up (78%). However, many also reported lack of possibilities for and/or low levels of empowerment. They were not aware of any decisions being made during their follow-up, had not received information about relevant patient associations, or had any conversations with healthcare professionals regarding their needs and wishes for their follow-up. Furthermore, almost 20% lacked information on and confidence in managing treatment-related side-effects, late complications and alarm symptoms.

Conclusion

Many respondents reported lack of possibilities for and/or low levels of empowerment in their cancer follow-up. This may have consequences for their quality of life and capabilities and opportunities for managing their own care.

1. Background

Having received a diagnosis of cancer and having gone through cancer treatment, will often leave a significant mark on the body and life of the person [1–3]. About 50% of people with cancer experience late complications, which can be both physical and psychosocial. These may appear during treatment or turn up several years after completed treatment [2].

When a person has been diagnosed with cancer, they will most likely enter a treatment program with a combination of e.g. surgical procedures, chemotherapy and radiation. After this initial treatment most people will enter a follow-up program [4].

From around 2015, routine follow-up in Denmark was changed. From follow-up with fixed intervals and a focus on relapse; to a more flexible and individualized follow-up with an increased focus on assessment of patients’ individual needs and rehabilitation. The aims of the new follow-up programs were among other things to support higher level of self-care and involvement from patients (e.g. [5]). The focus on individual needs, involvement and self-care may result in more empowerment of the person in follow-up. At the same time, it may also require more empowerment as it can be difficult to be involved without sufficient knowledge, confidence and intensions to act.

The aim of this study was to investigate the level of, opportunity for and value of empowerment among people with cancer in follow-up. To our knowledge, no studies have assessed the level of empowerment among cancer patients in Denmark attending follow-up, nor have we been able to identify any international studies assessing empowerment in representative national samples of people with cancer. International studies on empowerment among people with cancer have mostly been intervention studies, eliciting few details on empowerment or representing a narrowly selected patient group [6–11].

2. Materials And Methods

Study population

The target group was adults with a diagnosis of cancer attending follow-up in Denmark. To ensure a representative population, patients were identified from the nationwide Danish Cancer Registry (DCR) that entails data on all cancer incidences in Denmark [12].

Participants for the study were randomly selected among people with the following 10 cancer diagnosis: breast, prostate, colon and rectum, melanoma, bladder and urinary, brain and central nervous system, uterus, lung (including trachea), myelomatosis and ovaries. The first eight was chosen because they are the most frequent cancer diagnosis in Denmark (based on NORDCAN) [13]. The last two were included, as these diagnoses were represented among cancer patients participating as co-researchers in the project [14–16]. They were selected to have the same distribution of sex and age as people in their particular diagnosis group. In addition, they had to have been diagnosed between October 2013 – December 2016, be alive, registered with a complete address in Denmark, not being registered with name or address protection, and not declared incapable of managing their own affairs.

The questionnaire

All invitees received a link to the Cancer Patient Empowerment Questionnaire (the CPEQ) [16] together with questions on treatment(s), complications and socioeconomic characteristics. From the registry, we received information on diagnosis, gender and age.

The CPEQ was specifically developed for this study and aims at assessing empowerment among cancer patients in follow-up. The development of the CPEQ was based on theories by Zimmerman [17] and Tengland [18] defining empowerment as *"having control over the determinants of one's quality of life"* [18]. In the context of health-related control, an empowered person can be seen as someone who *"believes he or she is capable of understanding and influencing the relevant context/situation (intrapersonal component), understands how the healthcare system works and how to act to achieve desired outcomes (interactional component), and engages in relevant types of behaviors to exercise control (behavioral component)"* [17, 19]. Additionally, the CPEQ is based on the assumption that empowerment is a relational concept and therefore also assesses the healthcare professionals' support of empowerment [18, 19]. Finally, the CPEQ assess the degree to which patients find different empowerment manifestations important in their follow-up [18, 19].

The questionnaire was developed based on patient interviews [20], a review of empowerment [21], and reviews of empowerment questionnaires [19]. The developmental process has been described elsewhere [16].

The CPEQ consists of 67 items with categorial response options and 11 open ended questions and covers five different components of empowerment: i) *interactional* (patients' insight and ability to navigate), ii) *intrapersonal* (patients' perceived ability to handle necessary tasks and obstacles), iii) *behavioral* (patients' actions in relation to above mentioned), iv) *enablement* (health care professionals' (HCP) enablement in relation to above mentioned) and v) *value* (patients' perception of the value of empowerment in their follow-up) [16].

Data-collection

The questionnaire was distributed to patients via a digital mailbox called 'E-box' [E-boks] in November and December 2018. E-box is a mandatory secure electronic mailbox linked with people's unique civil registration numbers through which the public authorities communicate with the Danish population. One can become extent from E-box if one is having cognitive or physical disability, lack of access to internet, language barriers, or living abroad [22].

The email invitation included a personalized link directing patients to an online version of the survey questionnaire in the software system SurveyXact. Non-respondents received a reminder in E-box after approximately 14 days.

Data analysis

Participants and non-participants were compared with t-test (age) and chi-square test (gender, diagnosis, spreading/recurrence of cancer, marital status, children, country of birth, education, employment).

Frequencies for all items in the CPEQ were calculated using SPSS.

3. Results

Study population

From the Register we received a list of 3,416 patients. Three had passed away before receiving the questionnaire, 757 were exempt from the service by which we were to send out the questionnaire (E-box) and 19 informed us that they did not have cancer. Thus, 2,637 patients were eligible for the study and received the questionnaire and 1,418 patients (54%) responded. Subsequently, 376 participants were excluded from the analysis because they reported not being in follow-up, resulting in a final sample of 1,042 patients (Fig. 1).

Patients who had been extent from E-box were significantly older ($p < 0.0001$), more likely to be females ($p = 0.0005$) and having lung cancer ($p < 0.0001$), and less likely to have melanoma ($p < 0.0001$). No differences were found between non-respondents and respondents (see supplementary file 1).

Table 1 shows the characteristics of the respondents who reported not being in follow-up (n = 376) compared to those who reported being in follow-up (n = 1042). The distribution of diagnoses differed significantly ($p < 0.0001$) and patients with colon and rectum cancers, melanoma and uterus cancer reported more often not being in follow-up.

Table 1

Comparison of self-reported characteristics of patients who reported being in follow-up and those who reported not being in follow-up

		Respondents not in follow-up **(n = 376) N (%)**	**Participants in follow-up*** **(n = 1042) N (%)**	**P-value**
Gender	Female	232 (62)	598 (57)	0.1457
	Male	144 (38)	444 (43)	
Age (mean)		68 yrs	67 yrs	0.0454
Age (years)	20–49 years	23 (6)	85 (8)	0.0740
	50–59 years	52 (14)	154 (15)	
	60–69 years	126 (34)	369 (35)	
	70–79 years	122 (32)	339 (33)	
	80 +	53 (14)	95 (9)	
Diagnosis**	Breast cancer	38 (10)	144 (14)	< 0.0001
	Prostate cancer	46 (12)	126 (12)	
	Colon and rectum cancer	60 (16)	120 (12)	
	Melanoma	61 (16)	121 (12)	
	Bladder and urinary cancer	14 (4)	68 (7)	
	Brain and central nervous system cancer	3 (1)	17 (2)	
	Uterus cancer	87 (23)	58 (6)	
	Lung cancer (including trachea)	13 (4)	133 (13)	
	Ovarian and fallopian tube cancer, etc.	26 (7)	125 (12)	
	Multiple myeloma	28 (7)	130 (13)	
Time since diagnosis	0–2 years	19 (5)	70 (7)	0.416
	2–3 years	111 (30)	330 (32)	
	3–4 years	107 (29)	307 (30)	
	4–5 years	89 (24)	231 (22)	
	> 5 years and more	40 (11)	85 (8)	
	Missing	10 (3)	19 (2)	
Treatments received***	Surgery	311 (83)	760 (73)	< 0,001
	Radiation therapy	76 (20)	313 (30)	< 0,001
	Chemotherapy	111 (30)	482 (46)	< 0,001
	Bone marrow and stem cell transplantation	10 (3)	57 (6)	0,028
	(Anti) hormone therapy	21 (6)	132 (13)	< 0,001
	Immune therapy	21 (6)	71 (7)	0,407
	Experimental treatment	17 (5)	76 (7)	0,063
	Other treatments/not clearly defined	10 (3)	51 (5)	0,067
	No treatment	17 (5)	34 (3)	0,261

* Patients returning questionnaire, answering at least 1 CPEQ item, and reporting to be attending follow-up. Population included in the analysis.

** Diagnoses based on data from the Danish Cancer registry

*** Can add to more than hundred, since more answers were possible

		Respondents not in follow-up (n = 376) N (%)	Participants in follow-up* (n = 1042) N (%)	P-value
	Deleted (not a treatment or not clearly defined)	7 (2)	28 (3)	
	Missing	4 (1)	15 (1)	
Has the cancer spread?	No	317 (84)	774 (74)	< 0.001
	Yes, to the lymph gland	11 (3)	87 (8)	
	Yes, to other organs	14 (4)	63 (6)	
	Not relevant	1 (0)	11 (1)	
	I don’t know	27 (7)	97 (9)	
	Missing	6 (2)	10 (1)	
Has the cancer recurred after you have been told you were cancer free?	No	304 (81)	739 (71)	< 0.001
	Yes	18 (5)	96 (9)	
	I don’t know	42 (11)	175 (17)	
	Missing	12 (3)	32 (3)	
Marital status	Married/cohabiting	254 (68)	749 (72)	0.216
	In a relationship (living alone)	14 (4)	37 (4)	
	Divorced/single/widow(er)	73 (19)	197 (19)	
	Missing	35 (9)	59 (6)	
Children living at home	Yes	36 (10)	116 (11)	0.653
	No	176 (47)	516 (50)	
	Missing	164 (44)	410 (39)	
Country of birth	Denmark (including Greenland and The Faroe Islands)	329 (88)	942 (90)	0.650
	Other countries	12 (3)	40 (4)	
	Missing	35 (9)	60 (6)	
Education	Primary school	66 (18)	166 (16)	0.664
	High school	11 (3)	36 (4)	
	Skilled worker	95 (25)	245 (24)	
	Further education (3 years or less)	42 (11)	153 (15)	
	Shorter theoretical education (1–4 years)	89 (24)	265 (25)	
	Higher education (< 5 years)	33 (9)	106 (10)	
	Don’t know/not relevant	4 (1)	13 (1)	
	Missing	36 (10)	58 (6)	
Current employment	Full time	62 (17)	180 (17)	0.235
	Part time	25 (7)	100 (10)	
	Unemployed	8 (2)	10 (1)	
	Absent from work owing to illness	10 (3)	40 (4)	
	Old age pension	222 (59)	606 (58)	

* Patients returning questionnaire, answering at least 1 CPEQ item, and reporting to be attending follow-up. Population included in the analysis.

** Diagnoses based on data from the Danish Cancer registry

*** Can add to more than hundred, since more answers were possible

		Respondents not in follow-up (n = 376) N (%)	Participants in follow-up* (n = 1042) N (%)	P-value
	Early retirement pension	12 (3)	42 (4)	
	Other/student	1 (0)	9 (1)	
	Missing	36 (10)	55 (5)	
* Patients returning questionnaire, answering at least 1 CPEQ item, and reporting to be attending follow-up. Population included in the analysis.				
** Diagnoses based on data from the Danish Cancer registry				
*** Can add to more than hundred, since more answers were possible				

There were significantly more patients in follow-up where the cancer had spread (14% vs. 7%) or the cancer had recurred (9% vs. 5%).

There were no differences between patients who reported being in follow-up vs. not in follow-up regarding the collected sociodemographic variables (i.e., gender, marital status, children, education, employment, etc.).

In the final sample, more than half were women (57%) and the mean age was 67 years. Most patients had been diagnosed between two and four years ago (62%), the majority were born in Denmark (90%), were married or living with a partner (72%) and had retired (58%). Almost half of the participants were either educated as skilled workers (24%) or had a short theoretical education (1–4 years) (25%).

Empowerment

Table 2 presents the distribution of the 1042 cancer participants’ answers to the CPEQ items.

Table 2

Frequencies (%) of answers to the items assessing levels of, possibilities for and value of empowerment (n = 1042)

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT								
Knowledge about context	**1.** Are you in cancer follow-up (previously called control)?	*Yes* 100	*No* 0				*Don't know* 0	*Missing* 0
	2. Where does your follow-up take place?	*Hospital* 92	GP 6	Medical Specialist 3		*Other* 0	*Don't know* 2	*Missing* 1
	16. Do you know how to check your information in your electronic medical record?	*Yes* 68	*No* 26				*Not relevant* 3	*Missing* 2
Knowledge of resources, information, and possibilities of navigation.	**3.** Do you experience that there is a plan for your follow-up (such as a plan for time, place, frequency, and content of the follow-up visits)?	*Not at all* 3	*To a low degree* 3	*To some degree* 9	*To a high degree* 36	*To a very high degree* 47	*Not relevant* 1	*Missing* 1
	Do you know… **14.** …who to contact, if you have any doubts regarding your health?	2	3	16	33	43	1	2
	15. …how to get additional help outside the healthcare system if you need it (e.g. psychological help, rehabilitation, alternative treatment, patient associations, The Danish Cancer Society etc.)?	12	14	24	21	17	10	2
	In relation to your cancer, do you know… **17**. …where to find information about the illness, treatment and care?	6	10	30	32	18	4	2
	18. …in what situations to contact your doctor/hospital?	4	7	22	40	24	2	2
	19. Do you know what to pay attention to regarding the medicine you are taking (such as effects, side-effects, combination with other medicine, etc.)?	*Not at all* 5	*To a low degree* 5	*To some degree* 16	*To a high degree* 20	*To a very high degree* 13	*Not relevant/ I'm not taking any medicine* 39	*Missing* 2
Security and satisfaction	**4**. Are you satisfied with the plan, which has been made for your follow-up (such as a plan for time, place, frequency, and content of the follow-up visits)?	*Not at all* 1	*To a low degree* 2	*To some degree* 12	*To a high degree* 38	*To a very high degree* 41	*Not relevant/ We haven't discussed a plan* 4	*Missing* 1
	5. Are you satisfied with the point in time that the plan for your follow-up was made?	*Too early* 1	*Appropri-ate time* 88	*Too late* 1			*Not relevant/ We haven't discussed a plan* 8	*Missing* 2
	Do you feel at ease with… **6**. …the frequency of your appointments with the healthcare staff during your follow-up?	*Not at all* 1	*To a low degree* 3	*To some degree* 13	*To a high degree* 43	*To a very high degree* 37	*Not relevant* 1	*Missing* 2
	7. …the content of your follow-up?	1	4	14	43	35	1	2

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT								
Awareness of choices and possibilities	**During your follow-up have you or the healthcare professionals made decisions regarding…**	*Not at all*	*To a low degree*	*To some degree*	*To a high degree*	*To a very high degree*	*Not relevant*	*Missing*
	8. …treatment (either preventive or actual cancer treatment)?	30	4	9	19	13	22	4
	9. …treatment of side effects or late complications?	31	11	13	12	7	22	5
	10. …types of tests or examinations to be made at follow-up visits?	21	7	12	22	16	17	6
	11. …rehabilitation?	34	7	9	8	5	33	4
	12. …reconstructions after your treatment?	36	4	3	3	2	45	7
	13. …practical conditions relating to your follow-up (such as time/place/frequency)?	22	5	13	21	14	19	6
PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTRAPERSONAL COMPONENT								
Perceived ability to understand and handle information	**Do you feel capable of…**	*Not at all*	*To a low degree*	*To some degree*	*To a high degree*	*To a very high degree*	*Not relevant/ I haven't received any information material*	*Missing*
	20. …understanding the information you have received from the healthcare staff (both verbally and in writing)?	1	1	15	49	30	4	2
	21. …identifying what parts of information material from the healthcare system is relevant to you in your follow-up?	1	3	20	40	27	8	2
	Do you feel capable of…	*Not at all*	*To a low degree*	*To some degree*	*To a high degree*	*To a very high degree*	*Not relevant*	*Missing*
	22. …understanding the information regarding illness, treatment and care that you find on your own?	1	4	27	35	18	13	4
	23. …assessing the quality of the information material you find on your own?	2	6	32	29	13	15	4
Perceived ability to practice self-care	**Do you feel capable of…** **24**. …doing what is good for your body?	1	5	25	40	21	4	4
	25. …doing what is good for your mental wellbeing?	2	8	25	36	20	6	4
	26. …managing potential physical side-effects/late complications from your illness/treatment?	3	9	31	25	11	17	4
	27. …managing potential mental side-effects/late complications from your illness/treatment?	4	12	28	23	12	17	4

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT								
	28. …watching out for symptoms being signs of recurrence or worsening of your cancer illness?	3	9	25	33	24	4	4
Perceived ability to interact with health care professionals	**Do you feel capable of…** **29.** …assessing what you need from the healthcare professionals?	3	7	28	31	18	8	5
	30. …telling the healthcare professionals about your most important challenges?	3	7	22	31	21	10	5
	31. …participating in decisions regarding your health and treatment, if necessary?	2	5	18	40	26	6	4
PART B - EMPOWERMENT FACILITATORS: ENABLEMENT FROM THE HEALTH CARE SYSTEM								
Adequate information and support	**Have the healthcare professionals…**	*Not at all*	*To a low degree*	*To some degree*	*To a high degree*	*To a very high degree*	*Not relevant/ I haven't had a need*	*Missing*
	32. …explained things in an understandable language?	0	2	15	43	35	1	4
	33. …, in your perception, given honest responses?	0	1	8	46	39	1	4
	36. …told you about relevant patients associations?	15	14	17	19	16	14	5
	37. …given you written information that matched your situation and needs?	8	9	19	29	21	8	5
	38. …beforehand informed you about the side effects/late complications you have experienced (both orally and written)?	7	11	19	26	19	13	5
	40. …given you adequate supervision on how to take care of yourself at home (such as advice on diet, exercise and sleep)?	11	11	19	24	15	15	5
	41. …given you adequate information on how you can expect your cancer illness will affect your daily life?	12	14	19	20	14	15	6
Being listened to and taken seriously	**Have the healthcare professionals…** **34.** …been accommodating to your questions?	1	2	9	44	40	1	4
	35. …been accommodating to your experiences?	1	3	13	40	34	5	5
	39. …helped you ease/treat your side effects/late complications?	7	10	18	19	13	27	6

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT								
	42. …supported you in participating in decisions?	9	10	18	22	15	21	6
	43. Were the matters you felt you needed to discuss covered in your conversations with healthcare professionals?	*Not at all* 2	*To a low degree* 6	*To some degree* 22	*To a high degree* 38	*To a very high degree* 21	*Not relevant* 4	*Missing* 7
Support of relatives	**Have you missed that your relatives…** **44.** …were better prepared for what they could expect?	42	13	16	7	3	13	5
	45. …were listened to?	37	12	12	13	6	15	5
	46. …had more opportunities to talk to the healthcare professionals?	37	13	11	12	5	16	6
PART A – EMPOWERMENT OUTCOMES - THE BEHAVIORAL COMPONENT								
Participating in decision making	**During your follow-up, have you…** **47.** …had conversations with the healthcare professionals regarding your needs and wishes for your follow-up?	*Not at all* 17	*To a low degree* 11	*To some degree* 19	*To a high degree* 15	*To a very high degree* 7	*Not relevant/ I haven't had a need* 23	*Missing* 7
	48. …been involved in decisions (such as decisions on treatment of side effects or late-complications, preventive care or tests)?	16	9	16	16	8	28	7
	49. …declined recommended medicine or treatment because you believe it wasn't good for you?	44	4	5	4	4	32	7
	59. During your follow-up, have you faced decisions that you wished the healthcare professionals would make for you?	*Not at all* 43	*To a low degree* 9	*To some degree* 8	*To a high degree* 3	*To a very high degree* 2	*Not relevant* 29	*Missing* 6
Active communication and collaboration with the healthcare professionals	**During your follow-up…** **50**. …have you found solutions to your medical challenges in collaboration with the healthcare professionals?	*Not at all* 17	*To a low degree* 10	*To some degree* 16	*To a high degree* 13	*To a very high degree* 7	*Not relevant/ I haven't had a need* 30	*Missing* 7
	51. …have you told the healthcare professionals how you feel?	4	6	16	36	23	10	6
	52. …have you asked the healthcare professionals questions if you had doubts about care, treatment or illness?	6	6	15	30	20	16	7

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT

	53. …have you contacted the healthcare professionals because you had questions or concerns?	16	10	14	20	14	20	7
	54. …did you plan what you wanted to talk to the healthcare professionals about before your consultations?	7	6	18	28	21	13	7
	58. During your follow-up, have you told the healthcare professionals if you did not agree with them?	*Not at all* 16	*To a low degree* 8	*To some degree* 11	*To a high degree* 10	*To a very high degree* 4	*Not relevant/ I haven't disagreed with them* 45	*Missing* 6
Actively seeking additional support	**During your follow-up, have you…** **55.** …actively made an effort to receive referrals to relevant professionals (such as psychologists, physiotherapists, rehabilitation)?	*Not at all* 21	*To a low degree* 7	*To some degree* 9	*To a high degree* 13	*To a very high degree* 11	*Not relevant/ I haven't had a need* 34	*Missing* 7
	56. …had contact with other people who have or have had cancer to exchange experiences?	25	11	16	11	11	19	7
	57. …actively searched for other information than the information you received from the healthcare professionals?	22	12	18	12	11	18	7

PART C – THE VALUE OF EMPOWERMENT

	Is it important to you… **60.** …to have influence on the planning of your follow-up (such as a plan for time, place, frequency, and content of the follow-up visits)?	*Not at all* 7	*To a low degree* 13	*To some degree* 20	*To a high degree* 25	*To a very high degree* 18	*Not relevant* 11	*Missing* 6
	61. …to be prepared for how your health could affect your daily life after ended treatment?	3	4	13	33	25	15	6
	62. …that the healthcare staff takes time to talk to you about your daily life?	4	7	16	31	21	15	6
	63. …to know the details about your health, possible treatments and medicine?	2	3	10	32	33	13	6
	64. …to know about the decisions being made about your care and treatment?	2	3	6	31	36	15	7
	65. …to have an influence on the decisions being made about your care and treatment?	4	5	12	27	30	15	7

PART A – LEVELS OF EMPOWERMENT (EMPOWERMENT OUTCOMES) - THE INTERACTIONAL COMPONENT								
	66. …to have an influence on what tests you should have done?	9	9	15	24	24	13	7
	67. …that the healthcare professionals support you in doing things that you believe can improve your wellbeing (such as changes in diet, exercise etc.)?	4	5	16	26	23	19	7

The interactional component: Awareness and knowledge

Around 80% reported that they to a high degree experienced that there was a plan for their follow-up (item 3: 83%), were satisfied with the plan (item 4: 79%), and felt at ease with both the frequency of appointments (item 6: 80%) and the content of the follow-up (item 7: 78%).

Not all patients felt confident when it came to knowledge about accessing information. E.g. twenty-six percent did not know how to check their information in their electronic health record (item 16) or reported not knowing how to get additional help outside the healthcare system (item 15).

Regarding patients' awareness of decisions in their follow-up (items 8–13), large proportions of patients had not (not at all/to a low degree) experienced decisions being made regarding treatment (either preventive or actual cancer treatment) (34%), treatment of side effects or late complications (42%), types of tests or examinations (28%), rehabilitation (41%), reconstructions after treatment (40%), and practical conditions relating to the follow-up (27%).

The intrapersonal component: Confidence in own abilities

Sixty-six percent felt they were capable of participating in decisions regarding their health and treatment to a high degree (item 31). Patients reported being more confident when it came to understanding and assessing information material received from HCPs compared to the information materials they found themselves. Thus, seventy-nine percent reported to a high degree feeling capable of understanding the information they received from the HCPs (item 20) and 67% felt capable of identifying what parts of the information material was relevant to them (item 21). Whereas only around half of the patients reported to a high degree feeling capable of understanding (item 22: 53%) and assessing (item 23: 42%) the information they found on their own.

Some patients did not feel confident about selfcare. Eleven to 16% reported not at all/to a low degree feeling capable of managing physical side-effects, mental side-effects, or watching out for symptoms related to signs of recurrence or worsening of their cancer illness (items 26–28).

The behavioral component: Empowerment actions

Around half of the sample reported to a high degree having told HCPs how they felt (item 51: 59%), that they had asked the HCPs questions if they had doubts (item 52: 50%), and that they planned what they wanted to talk to HCPs about before consultations (item 54: 49%).

On the other hand, around a quarter of the patients reported that they had not at all/to a low degree been involved in any decisions during their follow-up (item 48: 25%) or had conversations with the HCPs regarding their needs and preferences for their follow-up (item 47: 28%).

In addition, 27% of the sample reported not at all/to a low degree having found solutions to medical challenges in collaboration with HCPs (item 50), and 24% did not tell the HCPs if they disagreed with them (item 58).

Regarding additional support, 28% of the patients reported that they had not made an effort to receive referrals to other relevant professionals at all/to a low degree (item 55), 36% had no contact with other cancer patients to exchange experiences (item 56) and 34% did not search actively for other information than the one received from HCPs (item 57).

Enablement from the healthcare system: Support from HCPs

Many patients felt HCPs explained things well and listened to them. More than 70% responded that HCPs to a high degree had explained things in an understandable language (item 32: 78%), given honest responses (item 33: 85%), and were accommodating to their questions (item 34: 84%) and experiences (item 35: 74%).

However, patients also reported some lack of adequate information and support from HCPs. Almost a fifth of the patients responded that HCPs not at all/to a low degree gave written information matching their situation and needs (item 37: 17%), had informed them beforehand on experienced side effects and late complications (item 38: 18%), supported them in participating in decisions (item 42: 19%), or helped ease and treat their side effects and late complications (item 39: 17%).

Around a quarter of the patients reported that HCPs had not at all/to a low degree told them about relevant patient associations (item 36: 29%), given adequate supervision on how to take care of one-self at home (item 40: 22%) or how to expect the cancer illness would affect their daily life (item 41: 26%).

The value of empowerment

Two thirds of the patients reported that it was very important to them ('to a high degree') to have knowledge about details on their health, possible treatments and medication (item 63: 65%), and the decisions being made about their care and treatment (item 64: 67%).

The value of other aspects seemed less important. Forty-three percent and 48%, respectively, reported that it was important to them to a high degree to have influence on the planning of their follow-up (item 60) or the tests they should have done (item 66).

5. Discussion

This nation-wide study is unique, as it included a large and randomly selected group of people in follow-up for their cancer and assessed the level of empowerment using the newly developed questionnaire CPEQ. This is one of few studies investigating the concept of empowerment in cancer follow-up, whereas previous studies have investigated cancer patients' needs and experiences in follow-up (e.g. [3, 23]) or needs and experiences with cancer care in general (e.g. [24]). Some of these surveys did cover elements related to empowerment, but not the full concept as covered in this study.

The participants in this survey reported generally feeling empowered in many areas. They also reported positive experiences with their follow-up. This is somewhat contradictory to previous studies of Danish cancer follow-up which suggest that far from all patients are satisfied with their follow-up [3, 25]. E.g., in one study, 51% reported not being adequately involved in decisions regarding their follow-up and 21% reported that they were being given responsibility for elements of their follow-up they considered to be the responsibility of the healthcare system [3].

Generally, patients in this study reported feeling quite knowledgeable when it came to understanding and navigating the health care context, as well as feeling at ease with the content, timing and way their follow-up was arranged. More than two thirds of the participants reported being confident in handling their follow-up, especially with respect to understanding and assessing the information received from the HCPs or participating in decisions. In general, they felt enabled and supported by the HCPs. Additionally, half of the participants reported being active in their communication with HCPs.

At the same time, several areas warrant further investigation and may indicate a need for improvement. Many had not experienced any decisions being made during their follow-up. It seems unlikely that no decisions have been made during their follow-up, and if patients are not aware of the decisions being made, it is difficult for them to be involved. Also, about a quarter of the participants reported that they had not at all or to a low degree participated in decision making. Previous studies on participation in decision making as a sign of empowerment are not straightforward; some studies describe these concepts as interconnected, suggesting patients should take on an active role to be empowered [26, 27], while other studies show that being un-involved in decisions can be a deliberate and preferred choice and thus not necessarily disempowering [28, 29]. Experiences from our previous studies indicate that the absence of empowerment-oriented behaviors are not necessarily indicating a low level of empowerment, since this could be a deliberate choice [16, 20].

Quite many of the respondents did not feel confident, when it came to handling side-effects and late complications. Another study of cancer follow-up in Denmark has shown that despite around 75% of patients considering examination and treatment of side-effects and late complications of high importance, only around 10% of these patients reported that late complications had been part of their latest follow-up consultation [25]. It seems that more focus on treatment, information and support in relation to side-effects and late complication are warranted.

Only a few patients reported that they had been informed about relevant patient associations or had had contact with other patients. From an empowerment perspective this may be unfortunate, since several studies have found that participating in patient groups could support empowerment, both as an important source of information and via social and relational effects [30–33]. However, the topic of patient organizations and social networks should be presented carefully and is not relevant to anybody since as many as 36% of cancer patients have reported not having a need to talk to other cancer patients [34].

Patients felt less confident when it came to knowing and articulating what they needed from the HCPs and 28% had not or to a low degree had conversations with HCPs regarding their needs and wishes for their follow-up. This could possibly be a problem, since one of the primary aims of the new follow-up programs is the co-creation of an individual plan for each patient, which should partly be based on the patients' articulation of their specific needs and challenges [4]. Patients may not know or believe that they could impact the planning of the follow-up program.

When looking at the distribution of answers to most items in the questionnaire, the numbers were strikingly evenly distributed between the response categories. This stresses the fact that patients have very diverse experiences, needs and opinions when it comes to empowerment related processes, and that empowerment is not a one-size fits all. Since patients and their cancer trajectory can vary in so many ways, it might not come as a surprise that the experiences and needs in follow-up are just as diverse. Other studies among cancer patients in follow-up confirmed diversities in preferences and stress the need for an individual organization matching expectations [25, 35].

Clinical implications

Based on the current study, it can be recommend for HCPs to further investigate what type of role(s) patients desire in their follow-up, since needs and expectations are very diverse [36]. Additionally, the results suggest that HCPs should have more focus on the treatment of side-effects and late complications, how patients' daily lives may be affected after treatment, and on creating awareness about the different decisions being made during follow-up.

Strengths and limitations

There were few differences when comparing respondents who attended follow-up and those who did not. However, some significant differences were found. For example, more patients with uterus cancer reported not being in follow-up, which might be related to the fact that symptoms of uterus cancer are often detectable early on, ensuring that more patients are diagnosed at an early stage [37] and therefore need shorter follow-up [38]. More patients with lung cancer reported being in follow-up than not, which might be related to the overall poor prognosis for lung cancer.

There is not a variable in the patient-register defining whether patients are in follow-up. Therefore, we had to rely on self-report, and it may not be all patients who are aware of whether they are in follow-up or not. Thus, we may have wrongfully excluded or included some patients.

By identifying patients from a patient registry, we ensured a random sample covering the whole country. However, the participants of the survey were not fully representative. Among the respondents, the elderly and ethnic minorities were underrepresented, whereas highly educated patients were overrepresented, which is often seen in Danish surveys [39, 40]. Since the elderly and maybe also ethnic minorities might be expected to report a lower level of empowerment than participants [41–44] and patients with a higher level of education are likely to report higher levels of empowerment [41], there is a risk that this has led to higher levels of reported empowerment than what is actually the case.

This may be supported by the fact that the qualitative input from the patient co-researchers and patients' interviewees presented a notably more 'negative picture' and previous studies showing that far from all patients felt safe or content with their follow-up in Denmark [25].

4. Conclusion

This paper reports the results of a survey using a comprehensive questionnaire providing a detailed insight into the level, possibilities and value of empowerment in cancer follow-up. The participants generally reported having quite a high level of empowerment within most areas and indicated positive experiences with their follow-up. However, some areas call for further attention. For example, they reported a lack of awareness of decisions, a lack of focus on and confidence in the HCPs' managing and treating side-effects and late complications, little information on patient associations, and difficulties with communication on wishes and needs for their follow-up. Furthermore, the participants had very diverse experiences, needs and opinions when it came to empowerment, which warrants efforts to ensure individualized communication and coordination of the follow-up.

Future studies should investigate whether differences in experiences, opinions and need for empowerment can be explained by characteristics, such as diagnoses, recurrence, time since diagnosis, age, education, etc. Additionally, comparisons between different follow-up programs and over time are interesting topics to pursue. Furthermore, since it can be challenging to include ethnic minority populations, elderly and patients with lower levels of education with the attempted method in this study, it would be highly relevant with more targeted studies for these specific population groups using qualitative methods.

Declarations

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Conflicts of interest

The authors report no conflicts of interest.

Availability of data and material

Data not publicly available

Code availability (Not applicable)

Authors' contributions

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [Nanna Bjerg Eskildsen], [Lone Ross] and [Anna Thit Johnsen]. The first draft of the manuscript was written by [Nanna Bjerg Eskildsen] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Ethics approval

The project was approved by the Danish Data Protection Agency (# 15/34025). The project was granted exemption from requiring ethics approval by the Regional Committee on Health Research Ethics (reference number: H-15000936), as questionnaire surveys do not require ethics approval according to Danish Law.

The study was performed in accordance with the ethical standards as laid down in the 1964 Declaration of Helsinki and its later amendments

Consent to participate

Informed consent was obtained from all individual participants included in the study.

Consent for publication

The participants has consented to publication of data from the project.

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Figures

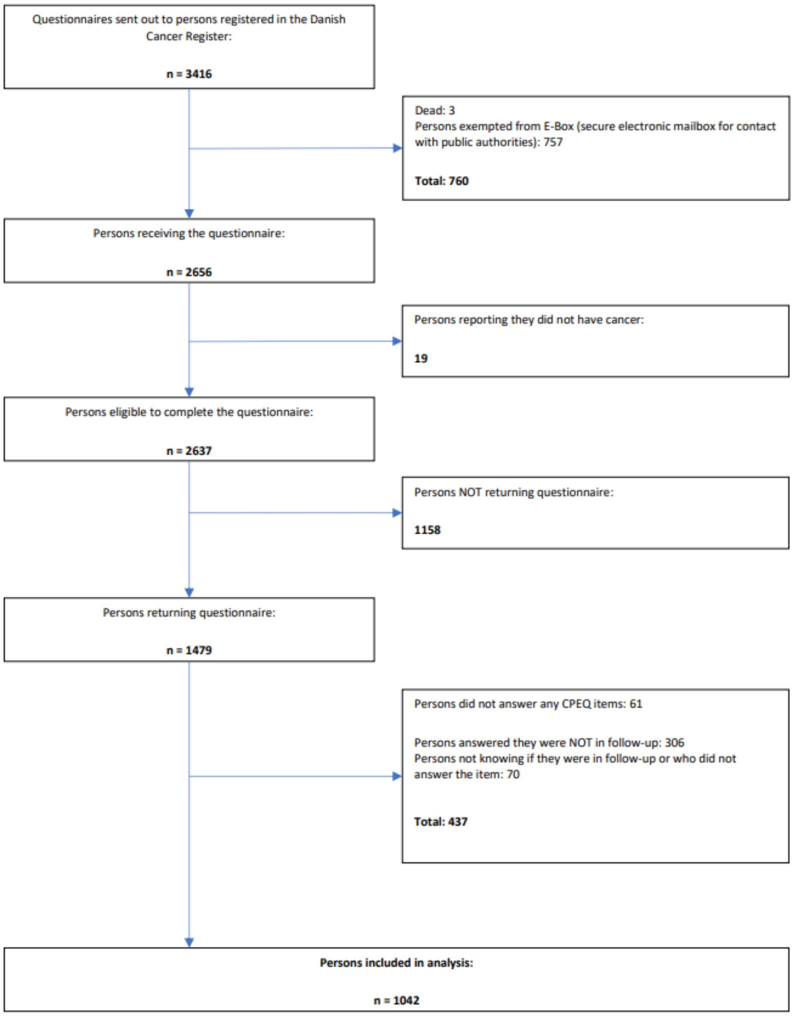

Figure 1

Flowchart

Supplementary Files

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- SupplementaryFile1.pdf