Diversity of Cancer-Related Identities in Long-Term Prostate Cancer Survivors after Radical Prostatectomy

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Research Article

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Abstract

Background

Individuals affected by cancer need to integrate this experience into their personal biography as their life progress after primary therapy, leading to substantial changes in self-perception. This study identified factors uniquely associated with 5 different cancer-related identities in order to improve the understanding of how self-perception in men affected by prostate cancer is associated with certain clinical and psychosocial characteristics.

Methods

In this cross-sectional study, long-term prostate cancer survivors after radical prostatectomy were asked to choose one of 5 cancer-related identities that described them best. Associations with sociodemographic, clinical, and psychological variables were investigated using multivariable logistic regression.

Results

3347 men (mean age 78.1 years) questioned on average 15.6 years after prostatectomy were included. Most men favored the terms "someone who has had cancer" (43.9%) which was associated with a mild disease course, and "patient" (26.3%) which was associated with ongoing therapy and biochemical disease recurrence. Self-descriptions, such as "cancer survivor" (16.8%), "cancer conqueror" (10.9%) and "victim" (2.1%) were less common. "Cancer survivor" was associated with high perceived disease severity (OR: 1.86 [1.44−2.40]). "Cancer survivor" and "cancer conqueror" were related to high benefit finding (OR: 1.89 [1.48−2.40], OR: 1.46 [1.12−1.89] respectively), and only "cancer conqueror" was associated with high well-being (OR: 1.84 [1.35−2.50]). Identification as "victim" was associated with psychological distress and low well-being (OR: 2.22 [1.15−4.31], OR: 0.38 [0.20−0.72] respectively). (all p < 0.05)

Conclusions

Although long-term survival is common among men affected by PCa, they display a large diversity in cancer-related identities, which are associated with unique clinical and psychological characteristics. These cancer-related identities and their distinctive properties are present and seem to interact with psychological well-being even after a long follow-up.

Background

With an aging population along with improvements in early detection and treatment, the numbers of

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cases cancer diagnosis and treatment become part of a continuing life story rather than its final chapter. However, living with cancer is in many cases still accompanied by a wide range of hardships deriving from factors such as pain, therapy side effects, accelerated aging, existential fears and distrust in one´s own body (2–5). This has placed growing importance on advising individuals affected by cancer on how to process their cancer experience and how to integrate it into their personal biography (6, 7). In this regard, particularly in the U.S., the concept of survivorship and identification as a "cancer survivor" has been advocated, while other characterizations, such as "patient" or "cancer victim", which connotate with a passive stance, have become more and more outdated (6–8). Accordingly, a shift away from these terms towards those that accentuate overcoming the disease, such as "cancer survivor" or "cancer conqueror", have been proposed for medical practice (7).

Deimling et al. found that self-identification as "survivor" was associated with increased positive affect, benefit finding and well-being in various types of cancers and that when given the choice, individuals affected by cancer often preferred the term "cancer survivor" over "patient". Consequently, they suggested that adapting a "survivor" identity is beneficial for mental health and disease coping.(7) However, subsequent research revealed that most individuals remain reluctant and identify more with the term "someone who has had cancer" than "cancer survivor" or "cancer conqueror" without a major drawback in overall well-being (8–10). Therefore, it was suggested that actively trying to impose a cancer related identity (CRI) might cause more harm than benefit.(11) Additionally, it has been shown that individuals continuously affected by clinical or emotional symptoms after primary treatment for cancer tend to still perceive themselves as "patients" (12). These mixed results complicate definitive recommendation of empowerment via specific CRIs.

Living with cancer is a major challenge for many men affected by prostate cancer (PCa). With 10-year survival almost unaltered in the majority of cases, long term continuation of life after diagnosis has become the norm for men diagnosed with PCa (13, 14). Nevertheless, regular follow-up visits, biochemical tumor recurrence rate of 20 to 50 % 10 years after primary therapy, as well as side effects from primary and adjuvant therapy may be a burden for many of those men(15–17). Thus, research on CRIs and their impact on well-being in men affected by PCa is of interest. Small US studies showed that 1 to 8 years after primary diagnosis, up to 35% of men affected by PCa favored the terms "cancer survivor" or "cancer conqueror" as self-description [5,6]. While identification as a "survivor" was associated with positive affect, identification as a "victim" was associated with negative affect. Results suggested that lower threat appraisal, thoughtful reflection and gaining an understanding through peers might be contributing factors in adopting a "survivor" identity.[4,5,6] However, data on clinical factors as well as psychological characteristics that might accompany the development of certain CRIs, other than a "cancer survivor" one, are still lacking.

This study assessed how men affected by PCa self-identify with regards to 5 different CRIs. Furthermore, associations of those CRIs with a broad set of sociodemographic characteristics, clinical factors, and psychosocial aspects were investigated, using data from a large German PCa database.

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Methods

Design and procedure

Data were gathered as part of the German research project 'Familial Prostate Cancer', which since 1993 has prospectively recruited PCa patients regardless of a family history of PCa via collaborating urologists and clinics. Further details about the research project and its multi-centric database has been described elsewhere (15, 18). In short, participants receive annual questionnaires concerning clinical, sociodemographic, and psychosocial information, with further clinical information being obtained through the corresponding treating urologist. The ethic committee of the TU Munich has approved this research project.

For the present study, cross-sectional data from the annual follow-up of 2019 was analyzed. By January of 2020, 4141 of 6168 participants (67.1.0%) had returned the questionnaire. From these, only participants who underwent radical prostatectomy as primary treatment and who answered the item regarding cancer identity were included.

Measures

Cancer-related identity

Following previous research, participants were asked to choose one of the following 5 CRIs describing them most suitable with regards to their cancer experience (7, 8, 11): "patient", "victim", "someone who has had cancer", "cancer survivor" and "cancer conqueror".

Sociodemographic and clinical characteristics

Sociodemographic data included: age at survey, school education, current partnership, and children. Clinical data included age at surgery, time since surgery, presence of a second primary cancer, family history of PCa (yes: at least one consanguine relative with PCa vs. no), PSA level at diagnosis, histopathological Gleason-Score, histopathological grading, organ-confined stage at RP according to TNM classification of 2002, biochemical recurrence (PSA level ≥ 0.2 ng/ml) during follow-up, biochemical recurrence at survey, discontinued PSA follow-up and ongoing PCa treatment at survey.

Depression and anxiety

Symptoms of depression and anxiety were assessed using the validated ultra-brief instruments Patient Health Questionnaire-2 (PHQ-2) and General Anxiety Disorder-2 (GAD-2) scale. For both scales (range 0–6), a cut-off score ≥ 3 indicates a clinical level of depression or anxiety, respectively (19, 20). Cronbach's alpha coefficients for PHQ-2 and GAD-2 scale were 0.65 and 0.75 respectively, representing satisfactory internal consistency.

Perceived severity of the disease

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The perceived severity of being affected by PCa was assessed with the single item "Having had prostate cancer is one of the worst things that happened to me in my life" (adapted from (21)). Participants were asked to answer on a four-point scale ranging from `strongly disagree´ (1) to 'strongly agree' (4). Responses (1) and (2) and responses (3) and (4) were combined to ´low perceived severity´ and `high perceived severity´, respectively.

Benefit finding

Benefit finding was assessed using one item with high factor loading and high face validity adapted from the German version of the 17-item benefit finding scale: "My prostate cancer has helped me become more focused on priorities, with a deeper sense of purpose in life".(22, 23) Participants were asked to answer on a five-point scale ranging from 'not at all' (1) to 'extremely' (5). Responses (1) and (2) and (3) to (5) were combined to ´low benefit finding´ and `high benefit finding´, respectively (24).

Well-being

Well-being was assessed using the single item "How much of the time during the past month did you feel happy"(25). Participants were asked to answer on a four-point scale ranging from 'none' (1) to 'all' (4). Responses (1) and (2) and (3) and (4) were combined to $low well\text{-}be \in g´$ and high well-being´, respectively.

Statistical analysis

Descriptive statistics were calculated for all study variables. Chi-square and Wilcoxon tests were applied for analyzing associations between the CRIs and sociodemographic, clinical, and psychological variables. Multivariable logistic regression was used to identify variables independently associated with each of the CRIs. Statistical significance was set at $p < 0.05$. All analyses were performed using SAS (Version 9.4).

Results

3347 men affected by PCa with a mean age at survey of 78.1 years (standard deviation (SD) = 6.3) and a mean follow-up 15.6 years (SD = 3.8) were included in the analysis (Table 1). Men self-identified most frequently as "someone who has had cancer" (43.9%) followed by "patient" (26.3%). The terms "cancer survivor" and "cancer conqueror" were favored by 16.8% and 10.9%, respectively. "Victim" was the least endorsed term (2.1%) (Fig. 1) .

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Table 1

Sociodemographic, clinical and psychological characteristics of the study sample (n = 3347).

	n	%
Sociodemographic factors		
*Age at survey (years)*M = 78.1 SD = 6.3		
≤ 70	375	11.2
> 70 ≤ 80	1599	47.8
> 80	1373	41.0
Educational level		
primary, secondary - low	1187	39.8
secondary - intermediate	519	17.4
secondary - high	362	12.2
tertiary	911	30.6
Partnership		
yes	3053	92.1
no	260	7.9
Children		
0	376	11.5
≥ 1	2901	88.5
Clinical characteristics		
Age at surgery (years)M = 62.5 SD = 6.1		
≤ 55	399	11.9
> 55 ≤ 65	1742	52.1
> 65	1206	36.0
*Time since surgery (years)*M = 15.6 SD = 3.8		
≤ 10	198	5.9
> 10 ≤ 15	1425	42.6
> 15 ≤ 20	1349	40.3

Note: *M*, mean; *SD*, standard deviation; *PCa*, prostate cancer; *PSA*, prostate specific antigen; *RP*, ~~e;~~ *GAD*, general anxiety disorder

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	n	%
> 20	375	11.2
Second primary cancer		
yes	430	12.9
no	2917	87.1
Family history of PCa		
yes	1297	38.8
no	2050	61.2
PSA level at diagnosis (ng/ml)		
≤ 4	307	9.9
> 4 ≤ 10	1870	60.1
> 10	934	30.0
Gleason score		
2−6	1424	50.5
7, 3 + 4 = 7, 4 + 3 = 7	1131	40.0
8−10	269	9.5
Grading		
G I	133	4.1
G II	2292	70.3
G III	833	25.6
Organ-confined stage at RP		
yes	2343	71.0
no	955	29.0
Biochemical recurrence during follow-up		
yes	1211	40.9
no	1749	59.1
Biochemical recurrence at survey		

Note: *M*, mean; *SD*, standard deviation; *PCa*, prostate cancer; *PSA*, prostate specific antigen; *RP*, ...e; *GAD*, general anxiety disorder

	n	%
yes	572	20.0
no	2295	80.0
Discontinued PSA follow-up		
yes	186	5.6
no	3161	94.4
Ongoing treatment at survey		
yes	423	12.9
no	2864	87.1
Psychosocial factors		
PHQ-2 (depression screening)		
positive screening (≥ 3)	469	14.8
negative screening (< 3)	2707	85.2
GAD-2 (anxiety disorder screening)		
positive screening (≥ 3)	360	11.4
negative screening (< 3)	2798	88.6
Perceived severity of disease		
low	1448	45.0
high	1770	55.0
Well-being		
low	1075	34.2
high	2067	65.8
Benefit Finding		
low	1823	56.0
high	1429	44.0

Note: *M*, mean; *SD*, standard deviation; *PCa*, prostate cancer; *PSA*, prostate specific antigen; *RP*, radical prostatectomy; *PHQ*, patient health questionnaire; *GAD*, general anxiety disorder

Men who self-identified as "someone who has had cancer" had the lowest percentage of biochemical recurrence during follow-up (31.6% vs. 40.9% on average). High perceived severity of the disease was

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reported most frequently by men self-identified as "cancer survivor" (68.9%) and "victim" (82.2%). While men self-identified as "cancer conqueror" expressed most often high well-being (75.2%), men self-identified as "cancer survivor" and "victim" expressed high well-being least often (59.0% and 34.8%, respectively). High benefit finding was found most often in men self-identified as "cancer survivor" or "cancer conqueror" (56.1%, 54.1%, respectively vs 44.0% on average, all p < 0.0001, Table 2).

Table 2
Comparison of key characteristics of the 5 cancer-related identities.

	Someone who has had cancer n = 1468 (%)	*Patient n = 882 (%)*	*Cancer survivor n = 561 (%)*	*Cancer conqueror n = 364 (%)*	*Victim n = 72 (%)*
Age at survey (years)**					
≤ 70	12.7	10.2	7.8	13.2	9.7
> 70 ≤ 80	49.4	48.2	43.5	45.9	52.8
> 80	37.9	41.6	48.7	40.9	37.5
Educational level**					
primary, secondary - low	36.3	38.8	46.0	45.1	52.5
secondary - intermediate	17.9	17.3	15.4	19.0	16.4
secondary - high	12.5	11.9	12.8	10.2	13.1
tertiary	33.3	32.0	25.8	25.7	18.0
Partnership					
yes	92.2	91.9	90.7	95.0	91.4
no	7.8	8.1	9.3	5.0	8.6
Children					
0	12.1	12.8	9.3	9.9	8.5
≥ 1	87.9	87.2	90.7	90.1	91.5
Age at surgery *(years)*					
≤ 55	13.8	10.0	8.9	13.5	12.5
> 55 ≤ 65	52.1	51.7	51.7	52.7	55.6
> 65	34.1	38.3	39.4	33.8	31.9
Time since surgery (years)***					
≤ 10	5.7	6.8	5.5	5.8	4.2

Note: **** p < .0001; *** p < .001; ** p < .01; * p < .05; *PCa*, prostate cancer; *FU*, follow-up; *PSA*, prostate), general anxiety disorder; *per.*, perceived

	Someone who has had cancer n = 1468 (%)	Patient n = 882 (%)	Cancer survivor n = 561 (%)	Cancer conqueror n = 364 (%)	Victim n = 72 (%)
> 10 ≤ 15	44.3	42.2	36.0	46.4	43.0
> 15 ≤ 20	40.7	40.8	41.7	34.9	41.7
> 20	9.3	10.2	16.8	12.9	11.1
Second primary cancer					
yes	11.7	12.5	15.5	13.7	16.7
no	88.3	87.5	84.5	86.3	83.3
Family history of PCa					
yes	40.5	35.9	38.2	40.4	33.3
no	59.5	64.1	61.8	59.6	66.7
Biochemical recurrence during FU****					
yes	31.6	49.1	51.3	39.6	54.1
no	68.4	50.9	48.7	60.4	45.9
Biochemical recurrence at survey****					
yes	13.7	29.6	21.9	16.8	25.9
no	86.3	70.4	78.1	83.2	74.1
Discontinued PSA follow-up					
yes	5.3	5.1	6.6	5.5	9.7
no	94.7	94.9	93.4	94.5	90.3
Ongoing treatment at survey****					
yes	6.2	19.7	18.3	13.0	23.2
no	93.8	80.3	81.7	87.0	76.8

Note: **** $p < .0001$; *** $p < .001$; ** $p < .01$; * $p < .05$; *PCa*, prostate cancer; *FU*, follow-up; *PSA*, prostate ..., general anxiety disorder; *per.*, perceived

	Someone who has had cancer n = 1468 (%)	Patient n = 882 (%)	Cancer survivor n = 561 (%)	Cancer conqueror n = 364 (%)	Victim n = 72 (%)
PHQ-2 (depression screening) ****					
positive screening (≥ 3)	12.0	15.0	19.7	13.0	39.1
negative screening (< 3)	88.0	85.0	80.3	87.0	60.9
GAD-2 (anxiety disorder screening) ****					
positive screening (≥ 3)	9.7	10.2	16.2	8.7	37.3
negative screening (< 3)	90.3	89.8	83.8	91.3	62.7
Perceived severity of disease****					
low	48.4	50.6	31.1	44.5	18.8
high	51.6	49.4	68.9	55.5	82.2
Well-being****					
low	32.3	34.5	41.0	24.8	65.2
high	67.7	65.5	59.0	75.2	34.8
Benefit finding****					
low	59.6	60.6	43.9	48.6	58.6
high	30.4	39.4	56.1	51.4	41.4

Note: **** p < .0001; *** p < .001; ** p < .01; * p < .05; *PCa*, prostate cancer; *FU*, follow-up; *PSA*, prostate specific antigen; *PHQ*, patient health questionnaire; *GAD*, general anxiety disorder; *per.*, perceived

Multivariable logistic regression analyses showed almost no associations between sociodemographic factors and the 5 CRIs. The two exceptions were an association between a "survivor" identity and higher age at survey and an association between identification as "someone who had cancer" and higher school education. Although, associations between clinical factors and the CRIs were seldom, there were the following notable exceptions. While men identifying as "someone who has had cancer" were less likely to have faced a more complicated follow-up (biochemical recurrence or ongoing therapy), men identifying

as "patient" were more likely to experience a current disease progress or ongoing therapy. Men with a "cancer survivor" identity were more likely to have experienced a biochemical recurrence during follow-up, but were less likely to have a current biochemical recurrence at survey. (Table 3) (all p < .05)

	Someone who has had cancer OR [95% CI]	Patient OR [95% CI]	Cancer survivor OR [95% CI]	Cancer conqueror OR [95% CI]	Victim OR [95% CI]
Age at survey (years) [ref: ≤70]					
>70 ≤ 80	-	-	1.47 [0.98−2.22]	-	-
>80	-	-	2.11 [1.39−3.20]	-	-
Educational level [ref: primary, sec. low]		-			
Secondary intermediate	1.37 [1.07−1.76]	-	-	-	-
Secondary high	1.16 [0.87−1.54]	-	-	-	-
Tertiary	1.34 [1.09−1.65]	-	-	-	-
Family history of PCa [ref: no]					
yes	1.20 [1.00-1.43]	-	-	-	-
Biochemical recurrence during FU *[ref: no]*					
yes	0.56 [0.46−0.68]	-	1.97 [1.49−2.61]	-	-
Biochemical recurrence at survey *[ref: no]*					
yes	-	1.93 [1.53−2.44]	0.68 [0.48−0.95]	-	-
Ongoing treatment at survey *[ref: no]*					

Note: *PCa*, prostate cancer; *PHQ*, patient health questionnaire; *FU*, follow-up; *ref*, reference; *OR*, odds

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	Someone who has had cancer OR [95% CI]	Patient OR [95% CI]	Cancer survivor OR [95% CI]	Cancer conqueror OR [95% CI]	Victim OR [95% CI]
yes	0.37 [0.27−0.51]	1.90 [1.45−2.47]	-	-	2.07 [1.06−4.04]
PHQ-2 (depression screening) [ref: negative screening (< 3)]					
positive screening (≥ 3)	-	-	-	-	2.22 [1.15−4.31]
Perceived severity of disease [ref: low]					
high	-	0.75 [0.61−0.91]	1.86 [1.44−2.40]	-	-
Well-being [ref: low]					
high	-	-	0.77 [0.61−0.99]	1.84 [1.35−2.50]	0.38 [0.20−0.72]
Benefit finding [ref: low]					
high	0.79 [0.66−0.94]	0.75 [0.62−0.92]	1.89 [1.48−2.40]	1.46 [1.12−1.89]	-

Note: *PCa*, prostate cancer; *PHQ*, patient health questionnaire; *FU*, follow-up; *ref*, reference; *OR*, odds ratio; *CI*, confidence interval; *sec.*, secondary

Associations with psychosocial factors were present for all CRIs. Whereas men with a "cancer survivor" and "cancer conqueror" identity were more likely to be considered to have high benefit finding, men identifying as "someone who has had cancer" and "patient" were less likely to be considered to have high benefit finding. Self-identification as "cancer survivor" was also associated with an increased likelihood of high perceived disease severity and a decreased likelihood of high well-being. "Cancer conqueror" was the only CRI associated with an increased likelihood of high well-being. Men self-identified as "victim" were more likely to report psychological distress and high perceived disease severity. The identities "conqueror" and "victim" were associated with the least number of significant factors. (Table 3) (all p < .05)

Discussion

During the past decades growing focus has been placed on assisting individuals diagnosed with cancer on mentally coping with the disease as they continue their life beyond the stage of primary therapy and successful recovery. In this regard it has been shown that there are different ways of perceiving this experience leading to a variety of cancer-related identities (CRIs). Especially meaning making by adopting an active CRI and identifying as a "cancer survivor" has been advocated as beneficial (7−9).

In this analysis of 3347 men affected by prostate cancer (PCa) with a mean follow-up of about 15 years since radical prostatectomy, most men self-identified as "someone who has had cancer" (43.9%) followed by "patient", "cancer survivor", and "cancer conqueror". Only few men believed that "victim" would describe them best (2.1%). These results are in accordance with previous research on men affected by PCa showing that, while the majority of such men favors a more neutral term, such as "someone who has had cancer" as self-description, identification with regards to a cancer experience may vary widely (8, 9). However, as we applied a forced choice response, we do not know whether men would find other self-descriptions nearly equally appropriate. It may be that men might choose more than one CRI. Thus, CRI not chosen do not necessarily imply negative appraisals.

Results indicated that men who preferred the more neutral term "someone who has had cancer" were more likely to have experienced PCa with an oncological uneventful follow-up (no biochemical recurrence) and less likely to report profound, positive changes derived from their cancer experience (benefit finding). These findings support previous studies finding that individuals who preferred a more neutral term considered their disease often as something unthreatening of their past and "hardly ever think about their disease" [5],(10). For men who self-identified as "someone who has had cancer", PCa did not hold the centrality in their life sufficient to trigger the development of an active CRI (26). Since PCa is generally linked with long term survival, many men prefer "someone who has had cancer" over terms such as "cancer survivor" as self-description in the present as well as in previous studies (11).

A characteristic adversity of PCa is that, despite an excellent survival prognosis, biochemical cancer recurrence, requiring subsequent therapy, is seen in a considerable number of cases even 10 years after primary therapy (17, 27). In this study sample at least a fifth reported a biochemical cancer recurrence at survey and/or an ongoing therapy. Men in this situation, characterized by cancer as a current medical condition rather than an overcome life event, were more likely to perceive themselves as "patient". This agrees with a study from Thong et al., showing that treatment, cancer recurrence or lingering cancer/therapy-related symptoms after primary cancer therapy were associated with self-identification as "patient" (12). Men who self-identified as "patients" were less likely to consider their disease to have high severity, and no association between self-identification as "patient" and psychological distress was found. In contrast to previous studies, this suggests that identification with the more passive term "patient" is not necessarily associated with a more demanding disease burden and that a general denunciation of the term for individuals affected by cancer might be premature (10, 12).

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Studies on cancer survivorship and CRIs have proposed that adapting the identity of a "survivor" is a sign of actively engaging and coping with the cancer experience (7). Analyses of narrative data have suggested on the one hand, that identification as "cancer survivor" is often based on having experienced the disease as a serious life event, and on the other hand, a feeling of having successfully overcome the disease (7, 28). These aspects are supported by the findings of this study showing that men who self-identified as "cancer survivor" were inclined to report high perceived disease severity. Further, these men were also more likely to have endured a biochemical recurrence during follow-up, while simultaneously being more likely to be biochemical recurrence-free at survey. This supports that overcoming a subjectively and objectively more stressing disease course may lead to the endorsement of a "survivor" identity. Moreover, previous research has suggested that adapting a "survivor" identity may bring forward positive changes driven by the disease experience (7, 10). These assumptions are supported by findings of this study showing an association between a "survivor" identification and high benefit finding. However, men favoring self-description as "survivor" were also less likely to report high well-being. These results contradict previous findings proposing a positive effect of adopting a "survivor" identity on psychological health and well-being. Consequently, findings here show that the implications of a "survivor" orientation may vary between individuals affected by cancer.

A previous review of CRIs pointed out that acceptance of the term "cancer survivor" derives partly from positive portrayal of the concept by survivorship movements in the media and support groups (11). It should be noted that cancer survivor culture and research on CRIs is mostly based in the U.S., while cultivation of the term "survivor" or its equivalent translations is rather seldom in Europe(11, 29). Limited exposure to a positive depiction of survivorship might lead to inter-individual and intercultural differences in the understanding of the term and concept (30). One should consider that without reference some individuals may choose a "cancer survivor" identity not as a sign of active coping, but rather to reflect the burden of being confronted by fundamental changes and a sense of near defeat derived from their cancer experience. Therefore, identification as "cancer survivor" might be for some an expression or even a cause of diminished psychological well-being.

In contrast to identification as a "cancer survivor", which seems to be influenced by an objectively and subjectively demanding disease course, endorsement of the term "cancer conqueror" was not associated with any clinical factors or the perceived disease severity. This suggests that adapting this kind of identity, putting further emphasis on actively defeating the disease, might not be grounded on a certain disease course but rather on personal character traits influencing the general outlook on life. This is supported by findings here showing that identification as a "cancer conqueror" is associated with high well-being as well as high benefit finding, which may reflect a generally optimistic attitude.

As in previous studies of men affected by PCa only a minority self-identified with the term "victim", stressing the seemingly pitiful fate of individuals diagnosed with cancer (8, 9). Most studies on the subject have found that endorsement of this submissive CRI is associated with psychological distress (7–10). This is supported by the findings from this analysis showing that men self-identifying as "victim"

and low well-being. It should be noted that while

these men were more likely to perceive the severity of their disease as high, objective clinical factors did not differ much between these men and men self-identifying as "patient", the group with the lowest perception of high disease severity.

Study findings must be considered within the limitations of the analysis. Limited by the cross-sectional design, causal assumptions on development of CRIs should be further investigated in longitudinal studies. By only including men primarily treated with radical prostatectomy generalization towards all men affected by PCa is limited and implications for other cancer types should be treated with caution. The variety in CRIs suggests that different terms may be equally appropriate in addressing men affected by PCa and that, though these men select a preferred identity when prompted, the remaining identities don't necessarily have any negative connotations and when given the choice some men would have picked several identities to describe themselves with regard to their cancer experience. Nevertheless, the CRIs were distinctively associated with different clinical circumstances and psychological factors.

Conclusion

Although long-term survival is common among men affected by PCa, they display a large diversity in CRIs that show unique associations with mainly clinical and psychological characteristics. These CRIs and their distinctive properties are present and seem to interact with psychological well-being even after a long follow-up. This demonstrates that an individual approach, which should include the evaluation of the patient's cancer related self-perception, is essential in the post clinical care of men affected by PCa in order to understand the personal impact of their cancer experience.

List Of Abbreviations

CRI - Cancer-related identity

PCa - Prostate cancer

Declarations

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References

1. Miller KD, Nogueira L, Mariotto AB, Rowland JH, Yabroff KR, Alfano CM, et al. Cancer treatment and survivorship statistics, 2019. CA Cancer J Clin. 2019;69(5):363-85.
2. Shapiro CL. Cancer Survivorship. N Engl J Med. 2018;379(25):2438-50.
3. Jung A, Nielsen ME, Crandell JL, Palmer MH, Smith SK, Bryant AL, et al. Health-related quality of life among non-muscle-invasive bladder cancer survivors: a population-based study. BJU Int. 2020;125(1):38-48.

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4. Bernat JK, Wittman DA, Hawley ST, Hamstra DA, Helfand AM, Haggstrom DA, et al. Symptom burden and information needs in prostate cancer survivors: a case for tailored long-term survivorship care. BJU Int. 2016;118(3):372-8.

5. Dinkel A, Herschbach P. Fear of Progression in Cancer Patients and Survivors. Recent Results Cancer Res. 2018;210:13-33.

6. Little M, Paul K, Jordens CFC, Sayers EJ. Survivorship and discourses of identity. Psycho-Oncol. 2002;11(2):170-8.

7. Deimling GT, Bowman KF, Wagner LJ. Cancer survivorship and identity among long-term survivors. Cancer Invest. 2007;25(8):758-65.

8. Bellizzi KM, Blank TO. Cancer-related identity and positive affect in survivors of prostate cancer. J Cancer Surviv. 2007;1(1):44-8.

9. Morris BA, Lepore SJ, Wilson B, Lieberman MA, Dunn J, Chambers SK. Adopting a survivor identity after cancer in a peer support context. J Cancer Surviv. 2014;8(3):427-36.

10. Park CL, Zlateva I, Blank TO. Self-identity after cancer: "survivor", "victim", "patient", and "person with cancer". J Gen Intern Med. 2009;24 Suppl 2:S430-5.

11. Cheung SY, Delfabbro P. Are you a cancer survivor? A review on cancer identity. J Cancer Surviv. 2016;10(4):759-71.

12. Thong MSY, Wolschon EM, Koch-Gallenkamp L, Waldmann A, Waldeyer-Sauerland M, Pritzkuleit R, et al. "Still a Cancer Patient"-Associations of Cancer Identity With Patient-Reported Outcomes and Health Care Use Among Cancer Survivors. JNCI Cancer Spectr. 2018;2(2):pky031.

13. N. Mottet RCNvdB, E. Briers, P. Cornford, M. De Santis, S. Fanti, S. Gillessen, et al. EAU - EANM - ESTRO - ESUR - SIOG Guidelines on Prostate Cancer. 2019.

14. Howlader N NA, Krapcho M, et al (eds). SEER Cancer Statistics Review, 1975-2016. National Cancer Institute, Bethesda, MD, . 2019.

15. Meissner VH, Herkommer K, Marten-Mittag B, Gschwend JE, Dinkel A. Prostate cancer-related anxiety in long-term survivors after radical prostatectomy. Journal of Cancer Survivorship. 2017;11(6):800-7.

16. Johansson E, Steineck G, Holmberg L, Johansson JE, Nyberg T, Ruutu M, et al. Long-term quality-of-life outcomes after radical prostatectomy or watchful waiting: the Scandinavian Prostate Cancer Group-4 randomised trial. Lancet Oncol. 2011;12(9):891-9.

17. Liesenfeld L, Kron M, Gschwend JE, Herkommer K. Prognostic Factors for Biochemical Recurrence More than 10 Years after Radical Prostatectomy. J Urology. 2017;197(1):143-8.

18. Paiss T, Herkommer K, Bock B, Heinz H, Vogel W, Kron M, et al. Association between the clinical presentation and epidemiological features of familial prostate cancer in patients selected for radical prostatectomy. Eur Urol. 2003;43(6):615-21.

19. Kroenke K, Spitzer RL, Williams JBW. The Patient Health Questionnaire-2 - Validity of a two-item depression screener. Med Care. 2003;41(11):1284-92.

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20. Kroenke K, Spitzer RL, Williams JBW, Monahan PO, Lowe B. Anxiety disorders in primary care: Prevalence, impairment, comorbidity, and detection. Ann Intern Med. 2007;146(5):317-25.

21. Vadaparampil ST, Jacobsen PB, Kash K, Watson IS, Saloup R, Pow-Sang J. Factors predicting prostate specific antigen testing among first-degree relatives of prostate cancer patients. Cancer Epidem Biomar. 2004;13(5):753-8.

22. Antoni MH, Lehman JM, Kilbourn KM, Boyers AE, Culver JL, Alferi SM, et al. Cognitive-behavioral stress management intervention decreases the prevalence of depression and enhances benefit finding among women under treatment for early-stage breast cancer. Health Psychol. 2001;20(1):20-32.

23. Mohamed EN, Böhmer, S. . Die deutsche Version der Benefit Finding Skala: Ihre psychometrischen Eigenschaften bei Tumorpatienten. Zeitschrift für Medizinische Psychologie. 2004;13 (2):85-91.

24. Jansen L, Hoffmeister M, Chang-Claude J, Brenner H, Arndt V. Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. Br J Cancer. 2011;105(8):1158-65.

25. Ryff CD, Keyes CL. The structure of psychological well-being revisited. J Pers Soc Psychol. 1995;69(4):721.

26. Reiland SA, Clark CB. Relationship between event type and mental health outcomes: Event centrality as mediator. Pers Indiv Differ. 2017;114:155-9.

27. Hruza M, Bermejo JL, Flinspach B, Schulze M, Teber D, Rumpelt HJ, et al. Long-term oncological outcomes after laparoscopic radical prostatectomy. BJU Int. 2013;111(2):271-80.

28. Khan NF, Harrison S, Rose PW, Ward A, Evans J. Interpretation and acceptance of the term 'cancer survivor': a United Kingdom-based qualitative study. Eur J Cancer Care (Engl). 2012;21(2):177-86.

29. Smith KC, Klassen AC, Coa KI, Hannum SM. The salience of cancer and the "survivor" identity for people who have completed acute cancer treatment: a qualitative study. J Cancer Surviv. 2016;10(3):457-66.

30. Berry LL, Davis SW, Flynn AG, Landercasper J, Deming KA. Is it time to reconsider the term "cancer survivor"? J Psychosoc Oncol. 2019;37(4):413-26.
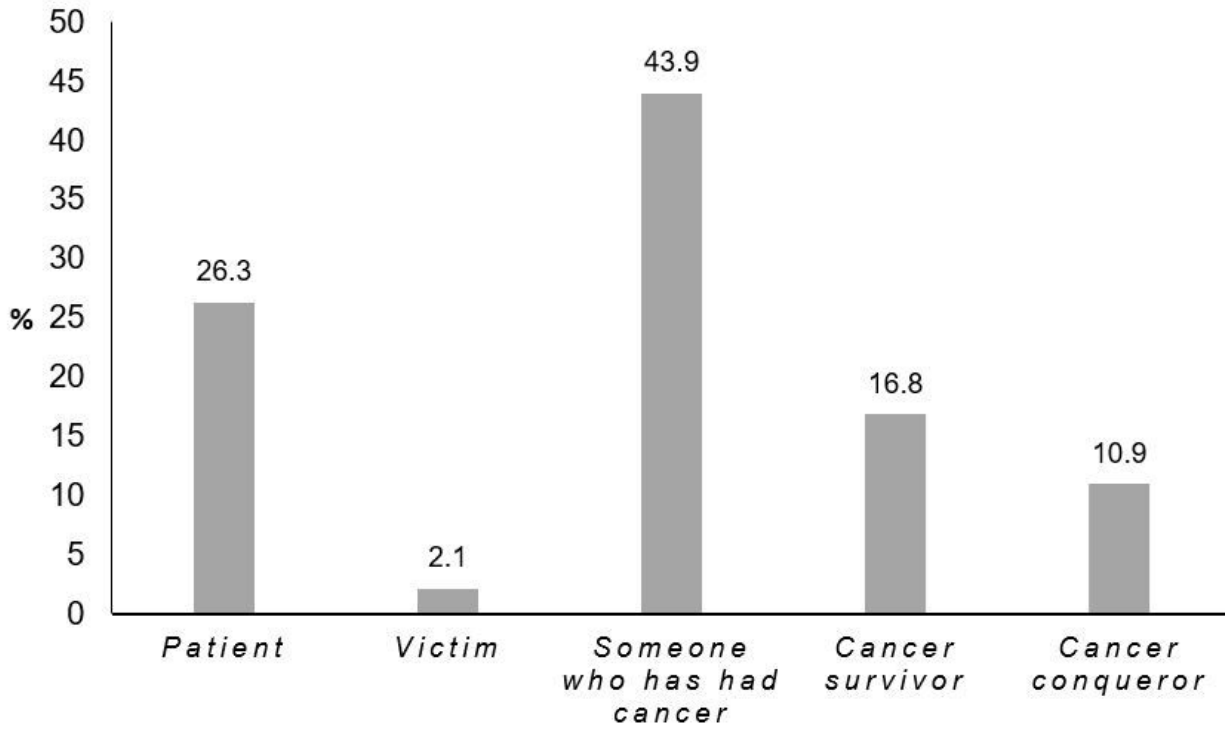
Figures

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Figure 1

Self-identification in the study sample of men affected by prostate cancer with a mean follow-up of 15.6 years.