

From surviving cancer to getting on with life

Testicular Cancer Survivors' perspectives on transition from follow-up care to long-term survivorship

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ABSTRACT

Title: From surviving cancer to getting on with life – Testicular Cancer Survivors' perspectives on transition from follow-up care to long-term survivorship.

BACKGROUND: Testicular cancer is a relatively rare cancer that commonly affects men between 18 to 35 years. With an increasing incidence and a high cure rate, a growing number of testicular cancer survivors are in need of specialized follow-up care. Literature on testicular cancer survivorship is limited and research is needed to increase understanding of their survivorship to identify unmet care needs and develop tailored interventions.

AIM: This study aimed to gain insight into the perspectives of testicular cancer survivors' transition from follow-up care to long-term survivorship.

METHODS: A qualitative design, using a grounded theory methodology, was chosen to explore patients' perspectives and to construct a theoretical model. Participants were purposefully and theoretically sampled from adult testicular cancer survivors in follow-up care or completion less than a year. In-depth, semi-structured interviews were conducted following an interview guide. Data were analyzed by constant comparison.

RESULTS: Twelve testicular cancer survivors were interviewed with a mean age of 35 years. From their perspectives a theoretical model is developed, involving two main processes: *Living beyond the sword of Damocles* and *Getting on with one's life*. The main processes are circular in nature, able to set each other in motion and alternate in position due the individual and his (life) experiences.

CONCLUSION: The main processes towards long-term survivorship have general characteristics. The transition itself is an individual journey. The constructed model can guide healthcare professionals and researchers involved in testicular cancer survivorship.

RECCOMENDATIONS: Healthcare professionals need to understand the individual transition and ensuing needs towards long-term survivorship to improve follow-up care. Tailored interventions can prevent and reduce unmet care needs. Oncology nursing is well-suited in advancing survivorship care due to their holistic view and coordinating role. Also, more integration of additional information and support is recommended.

Keywords: Testicular Neoplasms, Survivorship, Transitional Care, Cancer Survivors

SAMENVATTING

Titel: Van het overleven van kanker naar doorgaan met het leven – de opvattingen van zaadbalkankeroverlevenden over de transitie van follow-up zorg naar langdurige overleving.

ACHTERGROND: Zaadbalkanker is een relatief zeldzame kankersoort die voornamelijk bij mannen tussen de 18 en 35 jaar voorkomt. Gezien de stijgende incidentie en hoge genezingskans heeft een groeiende groep zaadbalkankeroverlevenden behoefte aan gespecialiseerde follow-up zorg. Echter is er weinig literatuur over het leven na zaadbalkanker. Meer onderzoek is nodig om de kennis te vergroten, onvervulde zorgbehoeften te herkennen en interventies op maat te ontwikkelen.

DOEL: Dit onderzoek is opgezet om meer inzicht te krijgen in de opvattingen van zaadbalkankeroverlevenden over hun transitie van follow-up zorg naar langdurige overleving.

METHODE: Een kwalitatief onderzoek met een gefundeerde theoriebenadering is gekozen om opvattingen van zaadbalkankeroverlevenden te verkennen en een theoretisch model te ontwikkelen. De steekproef is doelgericht getrokken en theoretisch geselecteerd uit een groep van volwassen zaadbalkankeroverlevenden die follow-up zorg volgden of dit minder dan een jaar geleden afronden. Semigestructureerde, diepte-interviews zijn uitgevoerd met een interviewleidraad. De verzamelde data is geanalyseerd door constante vergelijking.

RESULTATEN: Twaalf zaadbalkankeroverlevenden zijn geïnterviewd met een gemiddelde leeftijd van 35 jaar. Vanuit hun opvattingen is een theoretisch model ontwikkeld dat twee hoofdprocessen beschrijft: *Voorbij het zwaard van Damocles leven* en *Doorgaan met het leven*. Deze twee processen zijn circulair, in staat om elkaar in beweging te zetten en kunnen variëren in positie; afhankelijk van de individuele patiënt en (levens)ervaringen.

CONCLUSIE: De hoofdprocessen naar langdurige overleving hebben algemene kenmerken. De transitie zelf is een persoonlijke reis. Het theoretisch model kan sturing geven aan zorgverleners en onderzoekers die betrokken zijn bij zaadbalkankeroverlevenden.

AANBEVELINGEN: Zorgverleners moeten de individuele transitie en bijbehorende zorgbehoeften begrijpen om de follow-up zorg te kunnen verbeteren. Interventies op maat kunnen onvervulde zorgbehoeften voorkomen en verminderen. Oncologieverpleegkundigen zijn zeer geschikt in het verbeteren van de follow-up zorg door hun holistische kijk en coördinerende rol. Ook wordt meer integratie van aanvullende informatie en ondersteuning aanbevolen.

Trefwoorden: Zaadbalkanker, Overleving, Transitiezorg, Kankeroverlevers

INTRODUCTION AND RATIONALE

Although testicular cancer (TCa) is relatively rare, the incidence is increasing the last two decades with the highest incidence rates in Western and Northern Europe (1). In the Netherlands, the incidence rate of TCa in 2019 was ten cases per 100.000 man-years with a mean age of 35 years (2). TCa is most common among men ages 18 to 35 years, also known as adolescent and young adults (AYA) (3). When diagnosed early, TCa is one of the most treatable cancers (1). The treatment of TCa is orchiectomy and then around half of the patients will receive chemotherapy and/or radiotherapy (3). Given the relatively young age at diagnosis and a 10-year survival rate exceeding 95%, a growing number of TCa survivors require follow-up care after cancer treatment (1,4,5).

Unfortunately, cancer and its treatment can result in adverse and late effects and are of great impact on the physical, social, psychological and existential dimensions of TCa survivors' lives (5–8). Adverse effects are defined as long-term effects and late effects are defined as effects that manifest months to years after cancer treatment (9). Chemotherapy poses the greatest risk of physical late effects, including peripheral neuropathy, Raynaud phenomenon, hearing loss, tinnitus, pulmonary complications, cardiovascular disease, secondary malignant and chronic fatigue (10–12). Regardless of additional treatment, research shows that TCa survivors can suffer from sexual problems, including concerns about infertility, body image and sexual dysfunction (11–14). Besides treatment related effects, TCa survivors can also struggle with psychosocial problems (5,15). Quantitative studies demonstrate that TCa survivors experience higher levels of stress and anxiety in comparison with the general population (5,8,16), and fear of cancer recurrence (7,17,18). Although adverse and late effects can have a great impact, various quantitative studies demonstrate that the overall quality of life (QoL) of TCa survivors is similar to that of men from the general population (19,20). Even so, some studies question if it fully covers the population of TCa survivors (3,21,22), and more recent studies do show deterioration on certain QoL dimensions for a subset of TCa survivors (23,24).

Nonetheless, care after cancer treatment, or follow-up care, mostly comprises medical check-ups to monitor recurrence of disease and addresses adverse and late effects, ending after five to ten years (10,11). Subsequently, TCa survivors transit to long-term survivorship (25). Long-term survivorship is defined as survivors who are alive without evidence of disease for five years or more following their initial diagnosis. Care in long-term survivorship is not standardized and initiatives for supportive care are fragmented (26–28), leaving TCa survivors with unmet care needs at risk of symptom burden when transitioning to long-term survivorship (7,8,29). Prior studies report unmet care needs of TCa survivors regarding the (self-)management of adverse and late effects and the availability of community support services (7,30–33). In general, research on identifying and addressing cancer survivors'

needs (26,27,34), and long-term cancer survivorship (35,36) is limited. To the best of our knowledge, research about TCa survivors' perspectives on transition from follow-up care to long-term survivorship is unknown. In the Netherlands, further development of survivorship care and national awareness of survivors' struggles are outlined as key priorities by the National Taskforce Cancer Survivorship (28), and further studies are needed to develop tailored interventions for the increasing population of TCa survivors.

This qualitative, explorative study aimed to gain insight into the perspectives of TCa survivors regarding their transition from follow-up care to long-term survivorship and to develop a theoretical model of their transition which could inform healthcare professionals and intervention development.

METHODS

Study design

A qualitative design, using grounded theory methodology, was chosen to explore participants' perspectives on transition towards long-term survivorship and to construct a theoretical model that is grounded in, and derived from the data (37). A qualitative approach seemed fitting for the limited explored study area. With the grounded theory methodology the study sought to unfold comparative processes in the TCa survivors' descriptions (38).

Ethics

The study was approved by the Medical Research Ethics Committee (METC) of the University Medical Center Utrecht who waived the need for a full ethical review according to Medical Research Involving Human Subjects Act (WMO) (reference number METC 20/057).

Sample and recruitment

Between February and June 2020, TCa survivors who received follow-up care were selected and recruited from an academic oncology outpatient clinic in the Netherlands. Patients were eligible to participate if they were an adult (≥ 18 years), were treated for (recurrence of) TCa, had complete remission of TCa and were in follow-up care or completed follow-up care less than one year. Patients were excluded if they were unable to read and speak Dutch or had a mental or cognitive impairment. Patients were selected purposively and theoretical sampling following an inductive-iterative approach was used until theoretical saturation was obtained (38). Patients were selected with regard to variation in age, cancer treatment, follow-up duration, educational background and social status to achieve maximum variation. The diversity of the sample was based on literature and experts working in the clinical practice with TCa survivors (5,39,40).

Eligible survivors were asked to participate in the study during follow-up consultation by the clinical nurse practitioner (DZ). Those who expressed interest, received an e-mail with study information by the researcher (SW). If the patient agreed, the researcher (SW) telephoned the patient within two weeks to give further information. If the patient was willing to participate, an appointment was made. Non-responding patients received a voicemail and were contacted again within one week to prevent selection bias and elevate response. Of the sixteen eligible participants identified, twelve agreed to participate in the study. Among the non-participants, two declined and two did not respond to the voicemail.

Data collection

Data was collected with semi-structured, in-depth interviews using an interview guide. The guide contained a topic list and was designed by the research team (SW, SV and DZ). Topics were based on literature and opinions of clinical professionals experienced with TCa survivors (see table 1). A pilot-interview was conducted to validate the topic guide within the research team (SV, DZ, SW), not leading to any changes. All interviews started with the same open question to lower the threshold of TCa survivors to speak freely, "Can you describe what follow-up care means/has meant for you?". To collect demographic characteristics, interviews ended with closed questions on age, cancer treatment, follow-up duration, education and social status.

Table 1. Interview guide with topic list and prompts.

Topic heading	Prompts
<i>Experiences of the follow-up care itself</i>	How have you experienced the follow-up care? Can you tell me more about these experiences? Can you explain in your own words what follow-up care entails?
<i>Experiences and expectations towards the ending of follow-up care</i>	What does it mean to you that the follow-up care is nearing its end? What do you think of the idea that you will no longer have any follow-up care? What do you need to complete the follow-up care? <i>If the participant shows signs of anxiety of completing the follow-up care:</i> Why are you worried? Why do you find the completion difficult? How do you handle these worries? What will you do with these worries? <i>If the participant shows signs of readiness towards the completion of the follow-up care:</i> Why are you ready to complete the follow-up care?
<i>(Expectations of) Life after follow-up care</i>	What will you do after the completion of the follow-up care?

Initially, face-to-face interviewing was chosen for data collection. Due to the COVID-19 outbreak, the following interviews were web-based with end-to-end-encrypted video call software (WhatsApp). Firstly, participants were given the choice to conduct the interview at home or at the outpatient clinic; all participants chose the latter. Participants who were digitally interviewed received guidelines to optimize the interview setting at their home. All interviews were conducted by one researcher (SW), who was not involved in the patients' care. Interviews were recorded with an analog recording device and are only accessible by the research team (SW, SV and DZ). Informed consent was obtained before the start of the interview: written consent for the face-to-face interviews and audio recorded consent for the video calls.

Data analysis

Data collection and analyses alternated by using constant comparison analysis (37,38). Interviews were transcribed verbatim and anonymized by one researcher (SW). Data was analyzed independently by two researchers (SV and SW). Firstly, transcripts were read and re-read to get familiar with the data and obtain an overall view. During open coding, meaningful phrases were singled out line-by-line and in-vivo coded, leading to initial concepts and fragments (41). Axial coding collated the fragmented data with similar traits into categories. New data was compared with the constructed categories for further development, refinement and verification (37). Simultaneously, links between the categories were identified and structured within themes. A code tree divided the categories in main themes and themes. A preliminary model was constructed and compared with the original transcripts (38). The preliminary model and its themes were reviewed by the researchers, selecting the most prominent themes and illustrating vivid quotes in consensus. Finally, a theoretical model was defined. Throughout the entire research process, independently coded data was discussed by the researchers until consensus was reached. Furthermore, field notes and theoretical memos were used to continuously reflect on the data analyses.

Trustworthiness

To enhance trustworthiness various techniques were used (38,41). The interviewer was trained in qualitative interviewing techniques and the techniques were evaluated by the research team (DZ, SV) to enhance the validity. From the beginning of data collection and throughout the study, theoretical memos, field notes and an audit trail were logged by one researcher (SW) to increase transparency. One involved researcher (SV) is an expert on qualitative research, strengthening the methodological quality and accuracy by critically reviewing each stage in the research process. Investigator triangulation was used to enhance credibility and consistency. Vivid quotes were translated by a native English

speaker, further increasing consistency. Peers critically reviewed the research process and products on accuracy, to establish dependability of the interpretations. Guidelines for conducting qualitative studies established by the Standards for Reporting Qualitative Research (SRQR) were adopted (42).

RESULTS

A total of twelve survivors were included in the study (see Table 2). The men's ages ranged from 28 to 49 years, with a mean of 35 years. Most participants were in follow-up care during the study with a duration ranged from four months to nine years and two months, with a mean of three years and one month. In two participants follow-up care ended before the interview took place; and two participants had experienced recurrence of cancer. The interviews lasted between 36 and 83 minutes (mean 52 minutes).

Table 2. Demographic data.

Characteristics	N (=12)
Age (in years)	
18-29	3
30-39	7
40-49	2
Educational background ^a	
Vocational education and training (VET)	6
Higher education	6
Employment	
Full-time	10
Part-time	1
Unemployed	1
Social status	
Married	5
In a relationship	4
Single	2
Divorced	1
Cancer treatment(s)	
Surgery ^b	2
Surgery and chemotherapy	8
Surgery and radiotherapy	1
Surgery, chemotherapy and radiotherapy	1
Follow-up duration (in years) ^c	
0-1	1
1-2	2
2-3	3
4-5	2
>5	4

a. Education system in the Netherlands

b. Surgery: orchiectomy and/or lymphadenectomy

c. Since last start when having cancer recurrence

Theoretical model: Transition from follow-up care to long-term cancer survivorship

The transition is conceptualized as an individual and cyclical process, involving two main processes *Living beyond the sword of Damocles* and *Getting on with one's life* (see figure 1). The individuality of the transition is represented by the grand cog in which the patient rotates at their own pace from follow-up care towards long-term survivorship. None of the men moved at the same speed towards long-term survivorship and different personal reasons were given why they were able, or in some cases unable, to let go of follow-up care. But an overall pattern emerged, showing that all survivors were affected by the two main processes setting each other in motion. The speed and position of the processes can alternate due to the individual and his (life)experiences. The recurrence of cancer resets the grand cog, restarting the transition.

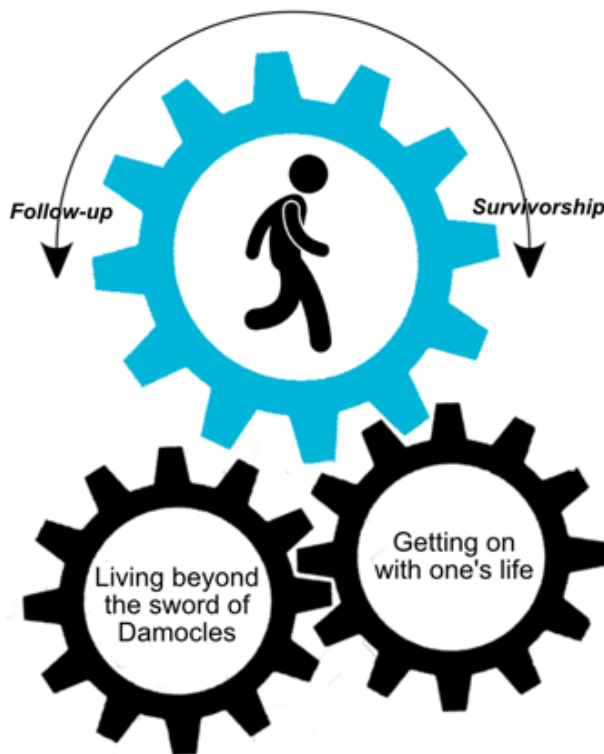


Figure 1. Transition model in cancer survivorship: from follow-up care to long-term survivorship

(Main) processes in transition from follow-up care to long-term survivorship

In total two main themes and six themes emerged from the interviews, translating into main processes and processes (see Table 3). The main process *Living beyond the sword of Damocles* involved transitioning from a period of feeling threatened by cancer to overcoming those threats. The main process *Getting on with one's life* can be described as transitioning from a period where cancer overruled their life to carrying on with normal life. Each main process will be further elucidated in the descriptions of the six processes.

Table 3. Summary of the key processes and processes of the transition from follow-up care to long-term survivorship

Key process	Process
<i>Living beyond the sword of Damocles</i>	Pointing a critical point whereas to be clean Finding reassurance in repeatedly good results Knowing that aid is always available if needed
<i>Getting on with one's life</i>	Restoring daily routines Regaining confidence in one's own body Mentally being able to move on

*Main process: Living beyond the sword of Damocles
Pointing a critical point whereas to be clean*

The transition of TCa survivors is partially characterized by a rational approach in which clear markers served as reference points to rebuild their shattered trust. Transitioning from fighting against cancer to overcoming cancer, involved setting a critical point where the risk of cancer recurrence was below a certain percentile. Many patients marked this point as a sense of *being clean*.

‘Well basically, I was clean when my tumor values were at a normal level’ (P9).

Survivors who had not reached this marker yet, described follow-up care as more intensive and stressful. Most participants who did overcome the critical point, noticed that follow-up care was less intensive and time between consultations was more spread out. The change in intensity gave several participants a positive outlook on their recovery process. As time passed, most participants were trusting more and more that they would stay clean.

‘As we are a year further, since my last treatment, I can only see it as an assurance ... especially since I have been clean for one and a half years’ (P5).

Half of the survivors perceived the lessening of follow-up care as cutting slowly the cord until being declared medically cured of cancer at the final follow-up consultation.

‘... you live for the moment that after five years, that you, they will say all is well... after five years you are cured’ (P6).

Finding reassurance in repeated good results

At the start of follow-up care all participants described more tension when waiting for results on tumor markers and imaging. Receiving repeated good results meant for all patients less tension and growing trust in their body. Several patients described this feeling of reassurance as *again knowing everything is all right*. Letting go of the reassurance found in good results was often found as a challenging part in transition to long-term survivorship. The two

participants who ended follow-up care requested a final checkup through imaging and tumor markers to know for sure that nothing was missed during follow-up care. One survivor who was not able to end follow-up care explained:

"Trust has taken a hit, so if every half year it can be corrected that is nice" (P3).

All survivors described that cancer recurrence will stay an uncertainty in their life. Nearly all men spoke of a need to accept that sometimes fear of cancer recurrence would appear. A few survivors spoke of ways they learned to channel their fear of cancer recurrence.

"I recognize the pattern and I know how I should react to myself, without getting myself completely worked up (P5)."

In more cases, survivors reached out for help from outside the hospital to develop tools in dealing with fear of cancer recurrence.

"...that when it reappears again, to be able to regulate it in a good way so that you will return to a normal sense as you normally would get from imaging and blood values" (P1).

Knowing that aid is always available if needed

Men felt that contacting their oncologist or clinical nurse about TCa after finishing follow-up care made more sense than going to their general practitioner. The knowledge that men could always return to the outpatient clinic, contributed in letting go of follow-up care and gave half of the patients a sense of security.

"There is always a chance that it will return, or something else, so it's good to have the check" (P10).

"... although I understand swimming and I am able to swim, it is just a nice feeling that the lifeguard is still nearby" (P1).

Main process: Getting on with one's life

Restoring daily routines

The process of restoring daily routines and prioritizing them above follow-up care, enabled men to get on with life. Through actively *picking up the pieces* and *at their own pace* restoring routines, men strove to get on with their daily lives. The majority of survivors spoke openly about their cancer history with close ones to receive understanding. Some survivors reached out for professional help when restoring daily routines were perceived as difficult. Overall, men described that restoring daily routines contributed to finding closure of the impact cancer had on their lives.

“It was really hard for me, after all these checks, to pick up my studies or finding a job... I really struggled with this, yes, in the beginning... it’s only after three years or so, I think, that emotionally I was ready to accept it all. I graduated and I have a job. Everything, the whole picture. That enables me to give it all closure” (P7).

During follow-up care all participants noticed a shift in prioritizing follow-up care to daily life. Several participants perceived this as *planning follow-up care around their daily life* and not planning their life around follow-up care. As time passed, a feeling of routine was felt by certain participants (*“going there is now the same as going to the bakery”* P6). Some of the survivors told that sometimes they even had forgotten their own follow-up appointment (*“to be honest, I even have forgotten to do the checks”* P3).

Regaining confidence in one’s own body

The transition meant dealing with the aftereffects of cancer treatment as participants sought to re-establish trust in their own body. For some patients having cancer felt as a betrayal by their body (*“Isn’t it weird that your body does this?”* P6). To trust their body again they needed *time* and their insecurities were treated in follow-up care.

Physical activities, patience and accepting physical changes helped men, experiencing adverse and late effects, in regaining confidence and physically getting on with their life. A few survivors did not experience aftereffects and said that having cancer could happen to anyone (*“your body is also able to make mistakes”* P8). Still, all patients described that regaining confidence in their own body helped them in various ways to reclaim their life.

The final phase of the transition consists of finding the enduring confidence in one’s own body and being able to no longer associate physical complaints with cancer.

“I immediately associated everything that I felt in my body with cancer... the trust was completely gone, and I had to rebuild it from almost nothing... finally it is this trust in my own body that I needed to keep” (P2).

Mentally being able to move on

Nearly all patients saw mental recovery as a large part of their follow-up care, besides the pure physical aspect of being cured of cancer.

“You can’t just let someone go after such a drastic event. Not only because of the medical side but also, for some people, because of the mental stuff. I think looking at both sides is a good idea” (P8).

Their transition towards becoming a long-term survivor was described as *personal* and *tailored by their needs*. Follow-up care helped survivors in *facing* and *accepting what happened*.

For the majority, mentally recovery was not explicitly seen as a part of the hospital treatment. Follow-up care helped them in reaching specialist mental care outside the hospital. Still, ending follow-up care meant the whole package: full physical and mental recovery from the threat of cancer. Several participants explained that the moment they realized they no longer needed the checks was the moment they could end follow-up care.

“If after a while it stops. I think that is quite normal actually, because it means your mentally ready... you have accepted that you no longer need the checks” (P9).

DISCUSSION

This study resulted in a theoretical model showing the transition of TCa survivors from follow-up care to long-term survivorship. Based on survivors' perspectives, comparative processes were identified involving two main processes: *Living beyond the sword of Damocles* and *Getting on with one's life*. The two processes were circular in nature, able to set each other in motion and alternated in position due to the individual and his (life) experiences.

Previous qualitative studies examining the transition in cancer survivorship, confirm the individuality and circularity of the transition and their main processes although age or gender differ (43–45). In addition, the results of an international Delphi-study amongst oncology nurses on nurses' perspectives of cancer survivorship mirrored the main processes and recalled the transition as an individual journey (27). These qualitative studies suggest that the transition in cancer survivorship is similar for various cancer survivors.

Our study focused on the transition and showcased its individual nature. The interviews suggested that coping styles can influence the individual transitioning speed and direction. Coping can be defined as a process of attempting to manage, master, tolerate, reduce or minimize the demands created by stressful events (46). Individual and environmental traits can influence the coping process, particularly ones marked by approach (adaptive, active attitude) and ones marked by avoidance (maladaptive, passive attitude) (47,48). The transition towards long-term survivorship can be identified as a stressful event, in which adaptive coping behavior can possibly aid. Quantitative studies into coping of TCa survivors demonstrated both the negative effect of avoidance-oriented-coping (49) and the positive effect of approach-oriented-coping (50) in survivorship.

This study has several strengths. Theoretical saturation on the theoretical model and all themes was achieved within the twelve interviews, which strengthened the transferability. Transferability was enhanced by a maximized and representative variety in the sample. Moreover, the duration and conditions of the interviews resulted in rich, thick descriptions

further enhancing transferability. Peer review and investigator triangulation enhanced the credibility and dependability. In addition, the use of SRQR enhanced dependability. Confirmability was achieved by evaluating the interview style, stage by stage review by other researchers and peers, recording an audit trail and reflecting on theoretical memos and field notes. A few limitations need to be considered. Despite all efforts to include all sixteen eligible survivors, two survivors refused to participate, and two survivors did not respond to the voicemail. Those refusing did not want to look back at their experiences, yet their perspectives could have been of value to the study. In addition, the interviews were conducted with two different techniques due to the COVID-19 outbreak. Although video calling still allowed face-to-face communication it was sometimes troubled by internet lag hindering synchronous interviewing (41). Yet research shows that web-based interviews does not have to affect in-depth interviewing (51,52).

The findings have implications for clinical practice regarding follow-up care. Firstly, to improve follow-up care, healthcare professionals need to understand TCa survivors' individual transition and their ensuing needs towards long-term survivorship. The theoretical model can assist in discovering individual cues that set the motion or alternate the position in the transition. Secondly, the study demonstrated the need for tailored interventions in preventing and reducing long-term effects for TCa survivors because the transition towards long-term survivorship encompasses more than physical recovery. Oncology nursing is well-suited to advance specialized survivorship care due to their holistic view of patientcare and coordinating role in healthcare provision (53). Thirdly, additional information and support should become more integrated in follow-up care (28,32). Several participants sought support outside the hospital and asked for additional information during follow-up care.

This qualitative study is a first exploration into the transition to long-term cancer survivorship. Future research is needed to further determine individual elements that can influence the direction and the speed of the cogs within the transition model and how early determination of individual needs can facilitate transition.

Our study gained insight into the transition of TCa survivors from follow-up care to long-term survivorship and discovered two main processes. The theoretical model explains the individuality and circularity of the transition which can be used as a framework for healthcare professionals providing follow-up care and as a guide for the research into and the development of tailored interventions for TCa survivors.

REFERENCES

1. Park JS, Kim J, Elghiaty A, Ham WS. Recent global trends in testicular cancer incidence and mortality. *Med (United States)*. 2018;97(37):1–7.
2. Landelijke cijfers testistumoren [Internet]. Registratie, N.K. 2019. Available from: <https://www.cijfersoverkanker.nl/>
3. Cheng L, Albers P, Berney DM, Feldman DR, Daugaard G, Gilligan T, et al. Testicular cancer. *Nat Rev Dis Prim*. 2018;4(1):29.
4. De Padova S, Rosti G, Scarpi E, Salvioni R, Amadori D, De Giorgi U. Expectations of survivors, caregivers and healthcare providers for testicular cancer survivorship and quality of life. *Tumori*. 2011;97(3):367–73.
5. Haugnes HS, Bosl GJ, Boer H, Gietema JA, Brydyø M, Oldenburg J, et al. Long-term and late effects of germ cell testicular cancer treatment and implications for follow-up. *J Clin Oncol*. 2012;30(30):3752–63.
6. Oechsle K, Hartmann M, Mehnert A, Oing C, Bokemeyer C, Vehling S. Symptom burden in long-term germ cell tumor survivors. *Support Care Cancer*. 2016;24(5):2243–50.
7. Smith A, King M, Butow P, LUCKETT T, Grimison P, Toner GC, et al. The prevalence and correlates of supportive care needs in testicular cancer survivors: A cross-sectional study. *Psychooncology*. 2013;22(11):2257–64.
8. Smith A, Rutherford C, Butow P, Olver I, LUCKETT T, Grimison P, et al. A systematic review of quantitative observational studies investigating psychological distress in testicular cancer survivors. *Psychooncology*. 2018;27(4):1129–37.
9. Aziz NM. Cancer survivorship research: State of knowledge, challenges and opportunities. *Acta Oncol (Madr)*. 2007;46(4):417–32.
10. Laguna MP, Albers P, Albrecht W, Algaba F, Bokemeyer C, Boormans JL, et al. Guideline Testicular Cancer [Internet]. European Association of Urology. 2019. Available from: <https://uroweb.org/guideline/testicular-cancer/>
11. Honecker F, Aparicio J, Berney D, Beyer J, Bokemeyer C, Cathomas R, et al. ESMO consensus conference on testicular germ cell cancer: Diagnosis, treatment and follow-up. *Ann Oncol*. 2018;29(8):1658–86.
12. Fung C, Dinh P, Ardeshir-Rouhani-Fard S, Schaffer K, Fossa SD, Travis LB. Toxicities Associated with Cisplatin-Based Chemotherapy and Radiotherapy in Long-Term Testicular Cancer Survivors. *Adv Urol*. 2018;2018:1–20.
13. Rossen P, Pedersen AF, Zachariae R, Von Der Maase H. Sexuality and body image in long-term survivors of testicular cancer. *Eur J Cancer*. 2012;48(4):571–8.
14. Eberhard J, Ståhl O, Cohn-Cedermark G, Cavallin-Ståhl E, Giwercman Y, Rylander L, et al. Sexual function in men treated for testicular cancer. *J Sex Med*. 2009;6(7):1979–89.
15. Smith A Ben, Butow P, Olver I, LUCKETT T, Grimison P, Toner GC, et al. The prevalence, severity, and correlates of psychological distress and impaired health-related quality of life following treatment for testicular cancer: a survivorship study. *J Cancer Surviv*. 2016;10(2):223–33.
16. Kreiberg M, Bandak M, Lauritsen J, Andersen KK, Skøtt JW, Johansen C, et al. Psychological stress in long-term testicular cancer survivors: a Danish nationwide cohort study. *J Cancer Surviv*. 2019;14(1):72–9.
17. Pedersen AF, Rossen P, Olesen F, Von Der Maase H, Vedsted P. Fear of recurrence and causal attributions in long-term survivors of testicular cancer. *Psychooncology*. 2012;21(11):1222–8.

18. Skaali T, Fosså SD, Bremnes R, Dahl O, Haaland CF, Hauge ER, et al. Fear of recurrence in long-term testicular cancer survivors. *Psychooncology*. 2009;18(6):580–8.
19. Rossen PB, Pedersen AF, Zachariae R, Von Der Maase H. Health-related quality of life in long-term survivors of testicular cancer. *J Clin Oncol*. 2009;27(35):5993–9.
20. Dahl AA, Mykletun A, Fosså SD. Quality of life in survivors of testicular cancer. *Urol Oncol Semin Orig Investig*. 2005;23(3):193–200.
21. Fleer J, Hoekstra HJ, Sleijfer DT, Hoekstra-Weebers JEHM. Quality of life of survivors of testicular germ cell cancer: A review of the literature. *Support Care Cancer*. 2004;12(7):476–86.
22. Mykletun A, Dahl AA, Haaland CF, Bremnes R, Dahl O, Klepp O, et al. Side effects and cancer-related stress determine quality of life in long-term survivors of testicular cancer. *J Clin Oncol*. 2005;23(13):3061–8.
23. Soon JA, Anton A, Torres J, Lawrence R, Parente P, McKendrick J, et al. Exploring the spectrum of late effects following radical orchidectomy for stage I testicular seminoma: a systematic review of the literature. *Support Care Cancer*. 2019;27(2):373–82.
24. Schepisi G, De Padova S, De Lisi D, Casadei C, Meggiolaro E, Ruffilli F, et al. Psychosocial issues in long-term survivors of testicular cancer. *Front Endocrinol (Lausanne)*. 2019;10:1–10.
25. Mullan F. Seasons of Survival: Reflections of a Physician with Cancer. *N Engl J Med*. 1985;313(4):270–3.
26. Nekhlyudov L, Ganz PA, Arora NK, Rowland JH. Going beyond being lost in transition: A decade of progress in cancer survivorship. *J Clin Oncol*. 2017;35(18):1978–81.
27. Truant TL, Fitch MI, O’Leary C, Stewart J. Global perspectives on cancer survivorship: From lost in transition to leading into the future. *Can Oncol Nurs J*. 2017;27(3):287–94.
28. Ezendam N, de Ligt K, Oerlemans S, Velthuis M. Kankerzorg in beeld - over leven met en na kanker. Integraal Kankercentrum Nederland (IKNL); 2019.
29. Travis LB, Beard C, Allan JM, Dahl AA, Feldman DR, Oldenburg J, et al. Testicular cancer survivorship: Research strategies and recommendations. *J Natl Cancer Inst*. 2010;102(15):1114–30.
30. Martin F, Turner A, Bourne C, Batehup L. Development and qualitative evaluation of a self-management workshop for testicular cancer survivor-initiated follow-up. *Oncol Nurs Forum*. 2013;40(1):14–23.
31. Bender JL, Wiljer D, To MJ, Bedard PL, Chung P, Jewett MAS, et al. Testicular cancer survivors’ supportive care needs and use of online support: A cross-sectional survey. *Support Care Cancer*. 2012;20(11):2737–46.
32. Shen AH, Howell D, Edwards E, Warde P, Matthew A, Jones JM. The experience of patients with early-stage testicular cancer during the transition from active treatment to follow-up surveillance. *Urol Oncol Semin Orig Investig*. 2016;34(4):11–20.
33. Alexis O, Adeleye AO, Worsley AJ. Men’s experiences of surviving testicular cancer: an integrated literature review. *J Cancer Surviv*. 2019;14(3):284–93.
34. Hewitt M, Greenfield S, Stovall E. *From Cancer Patient to Cancer Survivor - Lost in transition*. 1st ed. Washington, D.C.: The National Academies Press; 2005.
35. Jacobsen PB, Rowland JH, Paskett ED, Van Leeuwen F, Moskowitz C, Katta S, et al. Identification of Key Gaps in Cancer Survivorship Research: Findings From the American Society of Clinical Oncology Survey. *J Oncol Pract*. 2016;12(3):190–3.

36. Aiuppa L, Hewitt M, Nass SJ. Long-Term Survivorship Care After Cancer Treatment - Proceedings of a workshop. 1st ed. Washington, D.C.: National Academies Press (US); 2018.
37. Boeije H. Analysis in Qualitative Research. 1st ed. London: Sage Publications Ltd.; 2010.
38. Corbin J, Strauss A. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. 4th ed. Thousand Oaks, California (US): Sage Publications Inc.; 2015.
39. Smits-Seemann RR, Kaul S, Zamora ER, Wu YP, Kirchhoff AC. Barriers to follow-up care among survivors of adolescent and young adult cancer. *J Cancer Surviv.* 2017;11(1):126–32.
40. Nathan PC, Hayes-Lattin B, Sisler JJ, Hudson MM. Critical issues in transition and survivorship for adolescents and young adults with cancers. *Cancer.* 2011;117:2335–41.
41. Holloway I, Galving K. Qualitative research in nursing and healthcare. 4th ed. Chichester (UK): John Wiley & Sons, Ltd.; 2017.
42. O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: A synthesis of recommendations. *Acad Med.* 2014;89(9):1245–51.
43. Matheson L, Boulton M, Lavender V, Collins G, Mitchell-Floyd T, Watson E. The experiences of young adults with Hodgkin lymphoma transitioning to survivorship: A grounded theory study. *Oncol Nurs Forum.* 2016;
44. Matheson L, Boulton M, Lavender V, Protheroe A, Brand S, Wanat M, et al. Dismantling the present and future threats of testicular cancer: a grounded theory of positive and negative adjustment trajectories. *J Cancer Surviv.* 2016;10(1):194–205.
45. Sherman DW, Rosedale M, Haber J. Reclaiming life on one's own terms: A grounded theory study of the process of breast cancer survivorship. *Oncol Nurs Forum.* 2012;39(3):256–68.
46. Lazarus RS. Coping theory and research: Past, present, and future. *Psychosom Med.* 1993;55(3):234–47.
47. Taylor SE, Stanton AL. Coping Resources, Coping Processes, and Mental Health. *Annu Rev Clin Psychol.* 2007;3:377–401.
48. Parkes KR. Locus of control, cognitive appraisal, and coping in stressful episodes. *J Pers Soc Psychol.* 1984;46(3):655–68.
49. Rutskij R, Gaarden T, Bremnes R, Dahl O, Finset A, Fossa SD, et al. A study of coping in long-term testicular cancer survivors. *Psychol Heal Med.* 2010;15(2):146–58.
50. Hoyt MA, Gamarel KE, Saigal CS, Stanton AL. Goal Navigation, Approach-Oriented Coping, and Adjustment in Young Men with Testicular Cancer. *Ann Behav Med.* 2016;50(4):572–81.
51. Mirick RG, Wladkowski SP. Skype in qualitative interviews: Participant and researcher perspectives. *Qual Rep.* 2019;24(12):3061–72.
52. Vadi MG, Malkin MR, Lenart J, Stier GR, Gatling JW, Applegate RL. Comparison of web-based and face-to-face interviews for application to an anesthesiology training program: a pilot study. *Int J Med Educ.* 2016;7:102–8.
53. Haylock PJ. Evolving nursing science and practice in cancer survivorship. *Semin Oncol Nurs.* 2015;31(1):3–12.