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PSYCHOSEXUAL IDENTITY DEVELOPMENT IN ADOLESCENT AND YOUNG ADULT SURVIVORS OF TESTICULAR CANCER.

Section A: Which aspects of life are most affected following testicular cancer diagnosis and treatment?

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Section B: An Interpretative Phenomenological Analysis of the Psychosexual identity development in adolescent and young adult survivors of testicular cancer.

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Summary of Major Research Project

Section A: There is very little qualitative literature exploring the experiences of testicular cancer survivors (TCS), with most research focussing on the use of questionnaires and surveys. This literature review of qualitative research focussed on the experiences of TCS and amalgamated recurring themes. The findings identified themes of relationships, physical self-perception, masculinity, sexuality, fertility and clinical support. Some of these impacts also interact, such as fertility and masculinity. Clinical implications and future research recommendations are discussed.

Section B: Whilst there is little qualitative literature exploring the experiences of TCS, there is even less focussing on adolescent and young adult (AYA) TCS aged between 16-25. This is a critical period of an AYAs life-stage, where TC may be impacting their psychosexual identity development. This study explored the experience of AYA TCS in relation to their psychosexual identity development using Interpretative Phenomenological Analysis (IPA). Five Global Experiential Themes emerged: ‘Dealing with the shock’, ‘Fear and weight of responsibility’, ‘Those closest to me’ and ‘Sense of change’. An interpretation of the findings is that some AYA TCS develop characteristics typically associated with ‘traditional’ masculinity (e.g., stoicism and emotional detachment) whilst others moved away from ‘traditional’ masculinity features (e.g. violence and aggression). Research and clinical implications are discussed.

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Section A

Which aspects of life are most affected following testicular cancer diagnosis and treatment?

Word count: 7,689

Abstract

Background: Diagnosis and treatment of testicular cancer (TC) is known to have both physical and psychological effects on the survivor. This can include sexual dysfunction, fatigue, body image and challenges to the perceived sense of masculinity. Very little qualitative research has been completed exploring the experiences of testicular cancer survivors (TCS) following diagnosis and treatment. A systematic review of qualitative research exploring the experiences of TCS was conducted. The aim was to summarise the key themes of these research articles. **Method**: Literature was searched, screened and chosen against specific criteria from five databases. Nine articles were included in this review, with 7 purely qualitative and two mixed methods where only qualitative results were focused on using thematic synthesis. **Outcomes**: Six themes emerged from the research; relationships, physical self, sense of masculinity, sexuality, fertility, and clinical support. Some themes appeared to interact with each other, such as fertility and masculinity. **Discussion**: Treatment appears to lead to TCS challenging their identity and increasing anxiety over the future. Even when treatment is successful, TCS appear to be impacted in their ability to relate to others and in multiple aspects of their sexual development. Future recommendations involve psychological services helping to manage these burdens.

Keywords (Testicular, cancer, AYA, Psychosexual, Masculinity)

Which aspects of life are most affected following testicular cancer diagnosis and treatment?

Cancer charity Macmillan estimate that roughly 3 million people currently live with cancer in the UK, with numbers expected to rise to 4 million by 2030 (Macmillan, 2021). Between 2016 and 2018, there were 375,400 new cases of cancer in the UK alone (Cancer Research UK, 2021). The earlier the cancer is detected, the higher the likelihood the survivor will live longer (World Health Organisation, 2019). The early detection and treatment of cancer and promoting personalised after-care are some of the aims of the National Health Service in the UK (NHS) (NHS England, 2016) to increase the likelihood of survival, reduce the impact for the individual, as well as the cost of care to the NHS.

Testicular cancer (TC) accounted for 2354 cases between 2016 and 2018 in the UK. With advances in detection, treatment and aftercare, roughly 95% of men with testicular cancer survive after 5 years (Testicular Cancer Statistics, 2015). This review uses a definition of testicular cancer survivors (TCS) as those who were diagnosed and treated for TC, not those who had relapsed as the relapse impact often becomes the focus of the research.

People diagnosed with TC undergo removal of the testicle with the tumour (orchidectomy) as standard and, depending on the stage of cancer, may also need chemotherapy (Albers et al., 2005). Treatments at the various stages of TC can include (but are not limited to) chemotherapy, with advanced TC often requiring around 4 sessions (Feldman et al., 2008). Treatments for TC can be distressing for sufferers, with many complaining of increased anxiety and a strong fear of the cancer re-emerging (Smith et al., 2018).

Impact Of Testicular Cancer

The impact of TC has been widely researched quantitatively. TCS have been found to experience a myriad of challenges including both physical and psychological (Fossået al., 2018). Some physical impacts include sexual dysfunction, infertility and fatigue (Cheng et al., 2018). These can be exacerbated if the TCS received chemotherapy as part of their treatment (Cheng et al., 2018). Greenfield et al. (2010) completed a cross-sectional observational study comparing male cancer survivors with male controls. They found that sexual dysfunction, fatigue and QoL were impaired in male survivors of TC.

Other psychological impacts have been reported in relation to sexuality, body image, and challenges to their perceived sense of masculinity (Cappuccio et al., 2018; Alexiset al., 2020). Some TCS may maintain beliefs of infertility even when presented with evidence to the contrary (Alexis et al., 2020). Skoogh et al. (2001) found that following orchidectomy, unpartnered TCS were likely to experience feelings of loss and shame. Other studies have shown a clear connection between testicular anatomy and a sense of masculinity (e.g., Gurevich et al., 2004). Marilyn et al., (1995) found that loss of sexual function was psychologically distressing following orchidectomy, although Quality of Life (QoL) remained intact. When considering a definition of Quality of Life (QoL) as a self-reported ranting of importance of various life domains (Felce & Perry, 1995), these results suggest that the impact of TC may affect QoL for TCS through various means.

Quality Of Life

Research has yielded mixed results when observing QOL among TCS. For example, Llave (2021) measured social constraints and QOL in 162 TCS using questionnaires. They found that social constraints affected the QoL of single survivors more than partnered survivors. Orre (2008) found that TCS were roughly twice as likely to experience chronic cancer-related fatigue than the age-controlled general population. They also found this was more likely to occur in younger TCS who reported poor QoL, poor sexual satisfaction and psychological distress post-treatment.

However, Cappuccio et al. (2018) completed a literature review of QOL of TCS in research published between 1980 and May 2017 and concluded that there was no difference between the overall QoL of TCS and general population controls. They found that QoL may initially be impaired during diagnosis and treatment, but later returns to similar levels as observed in the general population. However, the QoL measures used within the literature reviewed varied, which may impair accurate comparisons. Gilligan (2015) also completed a literature review of the QoL of TCS between 1990 and 2015 and found that the QoL is comparable to the general population. They also concluded that TCS who underwent chemotherapy were more likely to experience chronic side effects such as fatigue and tinnitus. These side-effects may affect QoL, however the reported reduced quality of life may be due to the chemotherapy side-effects as opposed to TC itself (Frisina et al., 2016). Basten et al. (2001) found that TCS were likely to experience reduced sexual functioning, however found that there was no biological basis. Nord et al. (2004) also found that TCS were more likely to require medical support than the general population, again without a physical explanation. This suggests that some physical impacts may have psychological underpinnings, and that further follow-up research could untangle this phenomenon.

Fleer (2006) found that TCS were not found to be more vulnerable to impaired QoL. The study found that TCS did not experience lasting fatigue, reported good QoL and had high levels of spiritual well-being. The researcher did acknowledge that the results are based on questionnaires with generic questions. These questions may have low construct validity as they would not capture the impact of the cancer on the participants life. This supports the notion that research on cancer survivors, particularly TCS, would benefit from qualitative approaches which would provide rich, detailed information (Trainor & Graue, 2013).

Quantitative Research into The Psychological Impact

Many research studies utilised questionnaires and surveys when measuring the impact. This often yields results that show distinguishing features between the ages of TCS. For example, Greenfield et al., (2010) found that young TCS were more likely to self-report as less energetic, physically fit, and with reduced sexual function. Skoogh et al., (2011) also found that feelings of loss, uneasiness and shame following orchidectomy were more likely to be experienced by young (diagnosed between 16-25 years old), single TCS. This shows that the age of the TCS should be considered when observing the impact of TC.

However, questionnaire and survey-based research often come with limitations such as limiting the responses and a lack of rich information. An example is Vehling et al., (2021) who used an adapted Post Traumatic Growth Inventory (Maercker & Langner, 2001) to observe life changes in TCS. They found that roughly a third of their 164 participants reported at least one negative life change, and two thirds reported more positive changes. However, due to the measures used, the researchers were unable to explore simultaneous positive and negative changes within the same domain such, as increased closeness with others (positive domain) alongside an increased reliance on others (negative).

Ljungman et al (2019) observed sexual dysfunction and reproductive concerns in a sample of 111 TCS who responded to the research. The researchers used standardised measures such as the Patient Reported Outcome Measurement Information System (PROMIS) Sexual Function and Satisfaction measure (SexFS) (Weinfurt et al., 2015). Whilst the findings were that the majority of young TCS did not experience high levels of reproductive concern or reduced sexual functioning, the conclusions were limited as the cut-off score used to define sexual dysfunction is yet to be confirmed empirically.

Qualitative Research

There has been significantly less qualitative research observing the impact of testicular cancer, with most of the research opting to use questionnaires and surveys with large numbers of TCS. The above studies provide an example of the challenges experienced by researchers when using such measures to explore the depth and complexity of the psychological impact experienced by TCS. Qualitative approaches are known to provide unique insights that quantitative approaches struggle to capture. This includes the opportunity to observe phenomena that are missed by empirical research. Considering TCS, this can include observing complexities in the impact that can provide researchers and clinician with new insights (Silverman, 2020).

It is therefore important to consider what qualitative research can tell us about the impact of recovering from TC. Qualitative research has often varied in their aims such as exploring observing perceptions of masculinity and self-image (e.g., Carpentier et al., 2011) or psychosexual unmet needs (e.g. Dobinson et al., 2016). Completing a literature review of qualitative research can help amalgamate the recurring themes that appear, and thus provide new insights to guide future research.

Considering the number of TCS in the UK alone, as well as projections for the number of people living with cancer in future, there is likely to be an increase in psychological support needed for these individuals. Referrals to appropriate services will increase, and appropriate support will need to be implemented to reduce the physical and psychological impact of the disease.

Aims and Rationale

By reviewing qualitative research with TCS, an exploration into their experiences and potential impacts of cancer can be done in more detail. The aims are therefore as follows:

1. What themes emerge from research with TCS surrounding the impact on life?
2. To help summarise the specific impacts experiences by TCS,
3. To help guide future research and enhance patient care.

It is hoped that by addressing these points, this review can also answer the following question: Which aspects of life do TCS describe as being the most impacted following diagnosis and treatment?

Method

Literature Search Strategy

The databases Medline, PsycInfo, EBSCO, Web of Science and Google Scholar were searched on 12/12/2021. This date was also used as the end date range, with no lower limit to allow for breadth of exploration.

The following search items were used: (testicular cancer) AND (psycho) OR qualitative OR interview, or (testicular cancer) AND (Psycho OR qualitative OR interview).

The variation in search terms was to account for potential research articles that specified the qualitative approach, such as grounded theory (Corbin & Strauss, 2008). The searches were restricted to articles written in English and which were accessible at the time through a university account without needing to be purchased.

Inclusion And Exclusion Criteria

Table 1 summarises the inclusion and exclusion criteria for the research utilised in this review.

Table 1: Summary of inclusion and exclusion criteria for the research papers.

Inclusion Criteria	Exclusion Criteria
Must include TCS as participants,	Any duplicate research or where the focus is unrelated to the above areas (ascertained by reading the titles) were removed from the review,
Participants engaged in a Qualitative	The research was experimental in nature

aspect of the research, such as interviews.	(including RCT’s or only cross-sectional),
	Participants were not TCS (e.g., were currently in treatment or recently diagnosed and not treated).

Research Selection

There were two research articles that were not available in English (Kulpa et al., 2017 and Joly et al., 2019). Following screening of abstracts, roughly 25 out of 148 (17%) papers were inaccessible through the university account without needing to be purchased. The abstracts and references of the remaining articles were read. Following hand searching references, two studies were added to this review (Sheppard & Wylie, 2001; Saab et al., 2014).

This review also included research that utilised a mixed methods (quantitative and qualitative) approach (Sheppard & Wylie, 2001; Fleer et al., 2006). Only the qualitative findings of the research were considered as these fit with the aims of this review. Kristjanson et al., (2006) interviewed participants at different stages of the illness (early treatment, completing treatment, 12 months and 2 years following diagnosis and treatment). This review observed the themes that emerged following treatment as they related to our aims. Hauken et al. (2019) interviewed participants with different cancer-related diagnoses, however one of their participants was a TCS. Thus, this study was included in this review. Dobinson et al. (2016) also interviewed participants with various cancer-related diagnoses, however this review focussed on the 3 TCS participants included within the study.

Initial searches yielded 611 research articles. Following screening of titles and abstracts, 107 papers were read. 100 articles were then excluded and two were obtained through hand searching references, yielding a result of 9. This can be seen in the PRISMA diagram below (figure 1). All research utilised TCS survivors of varying ages, ranging from adolescent and young adult (AYA) to those aged over 50.

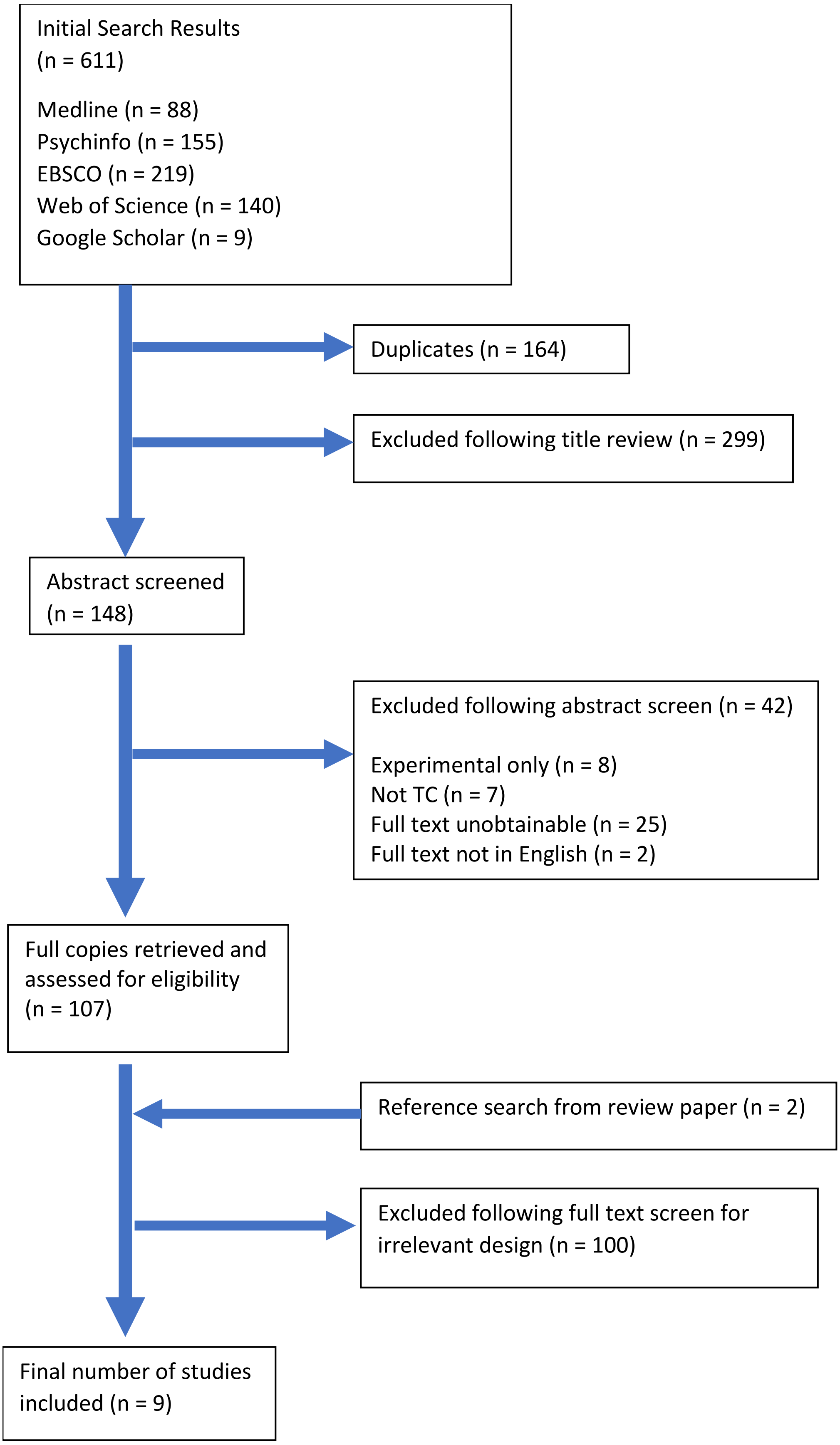
Initial Search Results
(n = 611)
Medline (n = 88)
Psychinfo (n = 155)
EBSCO (n = 219)
Web of Science (n = 140)
Google Scholar (n = 9)
Duplicates (n = 164)
Excluded following title review (n = 299)
Abstract screened
(n = 148)
Excluded following abstract screen (n = 42)
Experimental only (n = 8)
Not TC (n = 7)
Full text unobtainable (n = 25)
Full text not in English (n = 2)
Full copies retrieved and assessed for eligibility
(n = 107)
Reference search from review paper (n = 2)
Excluded following full text screen for irrelevant design (n = 100)
Final number of studies included (n = 9)

Figure 1: PRISMA diagram of review search process.

Research Quality Assessment

The Critical Appraisal Skills programme (CASP, 2018) checklist was used to assess the quality of the literature used (Appendix A). The checklist is a recognised tool for evaluating qualitative research quality and was used to evaluate the research quality, which was taken into account when considering the findings.

Structure of the Review

This review will present the main findings of each research article as a synthesis of the themes. This mainly involves themes surrounding the psychological impact of TC being amalgamated based on what is reported in the ‘results section’, similarly to other thematic synthesis research (Thomas & Harden, 2008). The theme development in this review is based on the frequency of the themes reported within and across the papers. Themes that were prominent within specific papers (as relevant to TCS as possible) were also reported. These themes will be initially summarised before critically appraising the research methodology of each study. Clinical and research implications arising from the review will then be discussed.

Review

Description Of Studies

This review looked at nine papers - seven which used a qualitative research design (Chapple & McPherson, 2004; Gurevich et al., 2004; Kristjanson et al., 2006; Carpentier et al., 2010; Saab et al., 2014; Dobinson et al., 2016; Hauken, et al., 2019). The remaining 2 were a mixed design involving interviewing some participants following questionnaires (Sheppard & Wylie, 2001; Fleer et al., 2006). A brief summary of each study can be seen in Table 2.

Table 2: Summary of the design, participants, measures, data analysis and key findings of the research.

Study	Design	Participants	Measures used	Data Analysis	Key Findings
Carpentier et al., 2010	Qualitative	• Purposefully sampled. • 21 AYA, • Aged between 18 - 34,	Semi-structured interviews.	Inductive thematic analysis with 3 raters.	Themes emerged as follows: • Embarrassment led participants to delay care-seeking, • Testicular cancer made participants feel different to others, ○ This difference to others resulted in feeling like 'damaged goods', • Difficulty in disclosing cancer,
Chapple & McPherson, 2004	Qualitative	• 45 men, • Aged between 20 - 55, • Purposefully sampled.	Semi structured interviews.	Analysis of themes conducted utilising computer program NUD*IST (Richards and Richards, 1993).	Reasons for accepting prosthesis at the time included: • Fear of loss of 'masculinity', • Self-image concerns, • Wanting to conceal loss of testicle, ○ Particularly with new sexual relationships, • Wanting to feel 'whole' again. Reasons for refusing prosthesis at the time included: • Understanding 'masculinity',

					fertility and sex would be unaffected in the long term, • Perceiving scrotal area looks identical to pre-orchidectomy, • Discouraged by doctors, • Not offered, • Perceiving prosthesis as ‘strange’, • Feeling more comfortable without second testicle, • Believing wives and partners would hardly notice a difference, • Out of sight so does not matter, • Safety concerns.
Dobinson et al., 2016	Qualitative	• Initially recruited through convenience sampling via online cancer registry, • Purposefully sampling later to substantiate theoretical construction and increase external	• Medical background questionnaires, • Semi structured interviews.	Grounded theory coding.	The following themes surrounding psychosexual unmet needs emerged: • Fertility concerns, including: ○ Needing age-appropriate information, ○ Needing to learn to cope psychologically with infertility, • Sexual communication, including:

	validity. • 3 TCS, • Aged between 30-40 at time of diagnosis,		o Communicating sexual issues to partners, o Asserting oneself sexually and fear of judgment, • Side effects, including: o Needing information on coping with sexual side effects, o Hair loss and fatigue, • Dating and disclosure, o Including concerns surrounding resuming dating and disclosing cancer history to new partners, • Relating to other AYAs, o Including opportunity to discuss social isolation of treatment, side effects and cancer impact on relationships, • Reconciling identity conflict, including: o Conflict between self-perceived and actual age,

					○ Information regarding normative sexual milestones.
Fleer et al., 2006	Mixed design (quantitative and qualitative)	• Purposefully sampling, • Interviews offered randomly to TCS who reported high or low impact of events scale scores, • 30 TCS participants interviewed	• Dutch impact of events scale (Brom and Kleber, 1985), • Impact of Traumatic Stressors Interview Schedule (ITSIS) (Kazak et al., 1996), • Semi structured interview used with 15 participants.	No formal qualitative analysis used.	Interview findings include: • No difference in the number of medical problems reported by TCS with clinically elevated cancer-related stress symptoms and those without, • TCS with elevated cancer-related stress symptoms spoke more often about their experiences to others than those without stress symptoms.
Gurevich et al., 2004	Qualitative	• Purposefully sampling, • 40 TCS • Aged between 17-62	Semi Structured interviews	Thematic decomposition (Stenner, 1993)	The following themes emerged: • Displaying an awareness of the impact of their anatomy/masculinity, • Rupturing sexuality/fertility, ○ Including a sense that the sexuality is fractured,

					• Insecurely held send of masculinity, ○ Including disconnecting and implicating their anatomy when constructing masculinity.
Hauken, et al., 2019	Qualitative - Interpretative Descriptive Design (IDD) (Hunt, 2009)	• Purposefully sampling, • 2 TCS participants (others were not relevant to this review), • Aged between 18 – 35	Semi Structured interviews	Thematic decomposition (Stenner, 1993) with Systematic Text Condensation (STC) (Malterud, 2012)	The following themes emerged from all survivors: • Hampering effects of cancer; ○ Impaired function and changed body, ○ Intrusive thoughts and feelings, ○ Negative impact on relationships. • Acknowledging what is important in life, ○ Changed perspectives, ○ Personal growth, ○ Significance of close relationships.
Kristjanson et al., 2006	Qualitative	• Purposefully sampling, • 32 TCS • All over the age of 16	Semi Structured interviews	Analysis of themes utilising NU*DIST software (Richards and	The following themes emerged in response to treatment and consequences of the disease and treatment: • Passive and trusting of medical

	Richards, 1993).	decisions without questioning, • Fear of the unknown, • Anger in response to the illness, • Sorrow and depression. The following themes emerged in response to the disease and treatment used to manage the illness: • Reaching out, ○ Including family and friends and deciding who to tell and how much they felt comfortable disclosing, • Information seeking, • Using health anchors to help manage their illness and feel healthier, ○ Including exercise and physical activity, • Planning a way forward, ○ Including focussing on goals and future plans to regain a sense of control. The following themes emerged in response

					to returning to a state of health and awareness following treatment: • Using precautionary health measures (such as testicular self-examination), • Fear of the disease reoccurring. The following themes emerged surrounding sources of support and stability the TCS identified as helpful through the various stages: • Health professional support, including: o Communication tone, o Information given, o Confidence in the professional competence, • Personal support, including: o The stabilising forces helping TCS re-establish their place in their respective social worlds.
Saab et al., 2014	Qualitative – Hermeneutic Phenomenological approach	• Purposefully sampled, • 8 TCS • Aged between 18 –	Interviews (Unspecified)	Conventional content analysis (Hsieh & Shannon, 2005)	The following themes emerged: • Cancer perception in Lebanese culture,

	50, • Average of 6 years after treatment.		○ Including prevailing societal beliefs about cancer, • Withholding disclosing diagnosis to others, • Cancer experience as a turning point, including: ○ No longer being able to engage in previous activities due to the fatigue and physical exhaustion. ○ Alternatively, an opportunity to make positive health-based changes in their lives, • Fertility, manhood and relationships, ○ Includes fertility as a determinant of their identity as men and partners, • Coping with cancer, ○ Includes using faith, partners, supporting clinicians, identifying with other men living with one testicle and seeking more cancer information,

					• Preserved aspects of life, including, o Acknowledging the temporary tiredness from cancer and its treatment, o Denial of a decline in sexual performance, o Lack of a need for a prosthesis and no sense of change in their body.
Sheppard and Wylie, 2001	Mixed design (quantitative and qualitative)	• Purposefully sampling, • 6 TCS and one wife • Aged between 21 - 39	Semi Structured interviews	Thematic analysis	The following themes emerged: • Perceived support of being in a committed relationship. o Included feeling ultimately closer to their partner, although there were some initial strains, • Concerns around sex being different following orchidectomy. • Body image issues, • Fertility concerns present in childless TCS, • No reduction in sexual interest, o However, some became less sexually active,

All studies reviewed appeared to utilise semi-structured interviews to elicit qualitative results, although this is less clear with Saab et al., (2014). All research utilised purposeful sampling of participants, with the ages of participants ranging from 16- 55 at time of interview.

The findings of the papers were amalgamated, and the seven themes that emerged can be seen in table 3.

Table 3: Summarised themes, study sources and example participant quote.

Theme	Papers contributing to theme	Quote from research as example
Relationships	Chapple & McPherson, 2004, Dobinson et al., 2016, Hauken et al., 2019, Saab et al., 2014 Sheppard and Wylie, 2001.	‘*…the issue of self-image and you know if you get into a relationship you don’t want to be sort of frightened of having sex without first telling the other person about your experience…*’ (Chapple & McPherson, 2004)
Physical self	Carpentier et al., 2010, Chapple & McPherson, 2004, Gurevich et al., 2004, Hauken, et al., 2019, Saab et al., 2014, Sheppard and Wylie, 2001.	‘*It’s like, a twelve-inch scar is hard to hide. That’s probably the biggest problem…*’ (Carpentier e al., 2010)
Impact on masculinity	Chapple & McPherson, 2004, Gurevich et al., 2004.	‘*It’s just that as a guy you don’t usually talk about things like that. Other guys don’t want to hear it, so you think, and they don’t want to be picturing that in their head either, right*?’ (Gurevich et

		al., 2004)
Sexuality	Chapple & McPherson, 2004, Dobinson et al., 2016, Gurevich et al., 2004, Saab et al., 2014, Sheppard and Wylie, 2001.	‘*An infertile man… the way people perceive him makes him want to beat himself… I suffered…a man is about sex and kids to a certain extent.*’ (Saab et al., 2014)
Fertility	Chapple & McPherson, 2004, Dobinson et al., 2016, Gurevich et al., 2004, Saab et al., 2014, Sheppard and Wylie, 2001.	*‘I think they’re [sperm] pretty sacred for a guy’* (Gurevich et al., 2014)
Positive impacts.	Chapple & McPherson, 2004, Kristjanson et al., 2006, Fleer et al., 2006, Saab et al., 2014, Hauken, et al., 2019, Sheppard and Wylie, 2001.	‘My life changed; it became healthy. I stopped smoking and stopped alcohol. . .I followed a totally different diet’ (Saab et al., 2014)
Clinical Support	Chapple & McPherson, 2004, Dobinson et al., 2016, Kristjanson et al., 2006,	*‘I was in total shock and just went with, just trusted this doctor’* (Kristjanson et al., 2006)

Relationships

Within the studies reviewed, several different TCS described how TC had a negative impact on their relationships. An example is with disclosure of their difficulties or diagnosis to others. Carpentier et al (2010) found that un-partnered TCS struggled to disclose their TC history to new romantic and sexual partners. One TCS described disclosing TC as more ‘intimate’ when compared to skin cancer. Timing of disclosure (for example during or after the first date) was also a concern expressed, with fears around evoking anger in the potential partner if the TCS withheld this information until later into the relationship. Dobinson et al., (2016) found TCS struggled to return to dating, with factors affecting the disclosure including predicted negative reactions and a sense of mistrust in the reaction of others, however this may be irrelevant to TCS and may relate to survivors of other forms of cancer. Some TCS interviewed in Kristjanson et al., (2006) withdrew socially, abstained from disclosing to others and struggled with recognising the added difficulties of being a man needing help. Some TCS become passive and accepted medical advice and support without questioning or attempts to understand the information. Saab et al., (2014) found that initially, many TCS did not disclose their diagnosis and treatment, keeping it even from siblings. One TCS stated he underwent kidney stone surgery or was losing his hair whilst showering to keep the truth from his parents. The majority of these TCS were selective in whom they disclosed to due to concerns of others in their village discussing it. Fleer et al (2006) also found that TCS not experiencing cancer-related stress symptoms were less likely to discuss their experiences with others, even though they showed similar levels of medical difficulties to those experiencing stress related symptoms. Dobinson et al., (2016) also found TCS described orchidectomy as a ‘hidden secret’, suggesting a lack of disclosure to others.

TCS also described difficulties in other relationships. Dobinson et al., (2016) found participants struggled to relate to other AYAs surrounding their sexual difficulties. These TCS described desiring the chance to be able to discuss cancers impact on their relationships, sexual side effects and social isolation but felt unable to do so. However, it is important to note that it is difficult to directly attribute this finding to TCS due to the varied participant diagnoses. One unpartnered TCS in Saab et al., (2014) described concerns about being rejected by potential romantic partners due to only having one testicle. Sheppard and Wylie (2001) described how some TCS detailed initial strains on romantic relationships, with one believing his former partner ended the relationship as ‘it made her feel strange’. Some also believed that being single would have negatively impacted their future experiences as they would struggle with taking the first step when meeting someone new.

Although having a partner during diagnosis and treatment appeared to limit some negative impacts, Dobinson et al., (2016) found TCS experienced difficulties with communicating sexual issues to their partners and desired guidance on doing so. A fear of judgment was noted as the barrier to this, with some reference to this being relevant to TCS. Carpentier et al. (2010) also found that partnered survivors struggled to disclose to other men. This was reportedly due to a perceived lack of a sense of severity of the topic, particularly when disclosure had led to others making jokes that negatively affected the TCS.

Physical Self

Several TCS reported issues with their bodies, including perceptions of their bodies following TC treatment. This has been evident in the TCS whom wanted to conceal their loss from others (e.g., Carpentier et al., 2010; Saab et al., 2014). Others have also described difficulties with fatigue and physical exhaustion (Saab et al., 2014; Dobinson et al., 2016). Some TCS in Carpentier et al., (2010) reported feeling different to other men, including a self-perception of being ‘damaged goods’ following orchidectomy. TCS in Chapple and McPherson (2004) described wanting to feel ‘whole’ again as a reason behind accepting a prosthesis, whilst others expressed body-image concerns being rectified through accepting a prosthesis. Gurevich et al., (2004) described how some TCS would consider their changed sexual anatomy when contemplating their masculinity, as it became a key factor. Sheppard and Wylie (2001) also found TCS would display body image concerns following treatment and concerns around the physical act of sex differing following treatment (although it would mechanically remain the same).

These perceptions appeared to link to other concerns, such as with fertility (Dobinson et al., 2016; Saab et al., 2014), particularly with un-partnered TCS (Shephard & Wylie, 2001). Gurevich et al., (2004) found that some participants equated having one testicle as contributing to them feeling like less of a man.

Impact on Masculinity

Another theme that emerged was the impact of TC on the TCS' sense of masculinity. Chapple and McPherson (2004) found that some TCS described a fear of losing their masculinity if they did not accept a prosthesis, suggesting the TC had contributed to an altered sense of masculinity. Gurevich et al., (2004) found that some TCS had their sense of masculinity heavily impacted, even after insertion of a prosthetic. The researchers described how the TCS seemed to associate the removal of a testicle with a reduction in masculinity and a sense of normalcy. As the testicle is associated with masculinity in the TCS, they seek to replace the previous testicular marker with either a prosthetic or an altered psychological perception of masculinity. This resulted in an insecurely held sense of masculinity, where TCS can disconnect their anatomy when constructing a 'new' sense of masculinity. Dobinson et al. (2016) also described how some participants felt TC had impacted and changed their sense of masculinity.

Fertility concerns have also been found to impact on male self-perceptions of masculinity (e.g., Gannon et al., 2004). Saab et al., (2014) found some TCS felt that their fertility was directly related to their identity as men and heterosexual partners. Thus, the risk or reality of infertility was impacting the sense of masculinity, particularly in a culture where becoming a father seemed to be a benchmark to reaching masculine adulthood and increasing positive perceptions from others (Birenbaum-Carmeli & Inhorn, 2009). Hauken et al., (2019) found that some TCS were experiencing intrusive thoughts and images relating to fears over their ability to start a family and even provide for themselves, which further suggests a negative impact of TC on masculinity, particularly within traditional heteronormative frameworks of masculinity. This links with concerns regarding fertility, another prominent theme.

Fertility

Fertility and related impacts were common amongst the studies reviewed. Gurevich et al. (2014) found that some TCS would experience fertility and masculine identity as connected. One TCS described feeling insecure around how his infertility meant he was not ‘good enough’. Other TCS described believing sperm is ‘sacred’ to men and another described disappointment in needing to consider adoption or artificial insemination as options to start a family. The TCS seemed to detail this hierarchy of paternity and masculinity, displaying a secondary impact on masculinity through fertility issues. As previously mentioned, some TCS in Saab et al. (2014) struggled to manage the connections between infertility and their sense of masculinity. However, unpartnered TCS in Sheppard and Wylie (2001) described fertility concerns, however partnered TCS did not. The researchers described this difference as likely due to age – with partnered TCS likely being older and so already fathered children so were not as concerned about fertility. Dobinson et al. (2016) found that concerns around infertility were common amongst TCS. They also found that some TCS felt that there was little to no support surrounding learning to cope psychologically with infertility, thus this was a psychosexual unmet need. They further described a need to learn more surrounding coping psychologically with infertility that was age-appropriate to their needs.

Sex and Sexuality

TCS also described negative impacts on their sex and sexuality. This includes previously mentioned TCS whom refused prosthesis as they wanted to conceal the loss of a testicle from new romantic relationships by avoiding intercourse (Chapple & McPherson, 2004). Dobinson et al., (2014) found several different sex-related impacts because of the TC. TCS interviewed reported difficulties in communicating with sexual partners, asserting oneself sexually and a fear of judgment from others. Some TCS also reported how managing sexual side effects (physically and psychologically) and lacking information surrounding normative sexual milestones were unmet psychosexual needs. TCS in Gurevich et al. (2004) described a ruptured sexuality/fertility in terms of current and perceived future functional challenges and reduced sexual pleasure and desire. One 19-year-old TCS described being told they would not have a ‘normal sex life’ again, and another described being unable to maintain an erection. TCS in Saab et al. (2014) however denied a decline in sexual performance, with only one seeming to describe short term difficulties in engaging in sexual contact during diagnosis and treatment. Some TCS in Sheppard and Wylie (2001) described concerns that sex would be ‘different’ following orchidectomy, and although there was no reduction in sexual interest, some TCS described becoming less sexually active.

Clinical Support

Dobinson et al., (2016) showed several influences from clinicians on negative impacts. This includes psychosexual unmet needs surrounding age-appropriate information, coping psychologically with infertility, coping with sexual side effects, opportunity to meet with other AYA TCS to discuss experience and information regarding normative sexual milestones. Although some TCS in Kristjanson et al. (2006) became passive and accepting of medical information, others began the process of information seeking. This included one TCS who described having not been told about his infertility unless he had asked radiologists directly. Other important factors emerged from this research regarding clinical support, including the communication tone of professionals, which TCS described as needing to be positive, realistic and respectful. One account involved a TCS experiencing two radiologists making a joke involving the size of the TCS's penis, although it is unclear from the research whether this was taken positively and helped to normalise the illness or was perceived negatively. Chapple and McPherson (2004) found that some doctors discouraged TCS from receiving prosthesis, which, considering some TCS became receptive to medical advice without question, may have influenced the TCS's decision surrounding prosthesis.

Positive Impacts

The above themes display some negative impacts, however there were also some reportedly positive impacts reported by TCS. Some TCS in Chapple and McPherson (2004) described refusing a prosthesis as they understood that their masculinity, fertility and sex challenges were to be experienced in the short term. Kristjanson et al. (2006) found that following treatment, some TCS would actively seek more information, reach out to friends and family, increase exercise and physical activity output and regain a sense of control on their lives with increased future planning. These findings correlate with Fleer et al. (2006) who found that TCS were more likely to disclose their experiences to others if experiencing elevated cancer-related stress symptoms. This suggests that these TCS would have been able to disclose to others, possibly reducing the negative impact a lack of disclosure brings. They also found that some TCS were able to utilise social support to re-establish their positioning within respective social worlds. Saab et al. (2014) found that some TCS would utilise partners, faith and identifying with other men who had experienced partial or full orchidectomy when learning to cope with cancer. Hauken et al. (2019) found that following the experience, some TCS began to re-evaluate what they felt was important in life. This included appreciating smaller things in life, becoming more aware of personal strengths and weaknesses and a deeper appreciation of close relationships.

There were some TCS whose relationship experience did not seem to negatively impact their treatment. Sheppard and Wylie (2001) also found that all participants described the experience of being in committed relationships as positive in helping them adjust to the physical impact of diagnosis and treatment. Chapple and McPherson (2004) found that some participants refused prosthesis due to an awareness that their partners or wives would hardly notice a difference. Some TCS in Kristjanson et al., (2006) found that disclosing to people close to them was relieving, but this seemed to depend on how close they felt to the other person. Some even found that this strengthened the relationships they had with others. Saab et al., (2014) found that most of the TCS they interviewed whom were in relationships experienced stronger relationships with romantic partners. One participant's wife even expressed 'not caring' about his potential infertility and wanted her husband to recover.

Methodological Critique

Most of the research was of a good standard according to the CASP (2018) checklist. All studies stated clear aims of the research and seemed to adopt appropriate research designs, with some variation in the analysis of data. All studies discussed some of their limitations and the conclusions seemed appropriate following the results. Table four summarises the critiques of each study, including the limitations and CASP qualitative checklist (CASP, 2018).

Table 4: Summary of critiques of each research study.

Study	Design	Inclusion/Exclusion Criteria	Results	Limitations	CASP Qualitative Criteria
Carpentier et al., 2010	Qualitative	Inclusion criteria as follows: • Completion of treatment for TC within the past 3–36 months, • 18–34 years of age, • English speaking.	Through analysis section with main themes and quotes supporting considerations.	Researchers considered the following limitation: • Small sample size, • Single recruitment site,	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Chapple and McPherson, 2004	Qualitative	Inclusion/exclusion criteria not specified (aside from TCS)	Thorough analysis section with themes outlined and quotes supporting considerations.	Researchers considered the following limitations: • Some TCS were diagnosed ‘many years ago’, which may suggest some attrition of memory, • Acknowledgement that there are many forms of ‘masculinity’.	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Dobinson et al., 2016	Qualitative	Inclusion criteria specified as follows: • AYA cancer survivors aged 15–45 when diagnosed,	Thorough analysis section with themes outlined and quotes supporting	Researchers considered the following limitations: • Possible interviewer effects,	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not

		• Currently over 18 years of age, Minimum of 6 months between the conclusion of primary treatment and research participation.	considerations. At times very difficult to distinguish specific diagnosis related difficulties.	• Recruitment issues leading to difficulty in purposive sampling of all participants.	discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Fleer et al., 2006	Mixed design (quantitative and qualitative)	Exclusion criteria stated as: • Younger than 18 years old, • Language barriers, • Having completed treatment less than 3 months ago.	Results appear almost exclusively from quantitative outcomes. No qualitative analysis of themes occurred. No interview quotes utilised to support qualitative findings.	Researchers considered the following limitation for the qualitative aspects: • Results should be considered preliminary – due to low participant numbers.	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? NO 9. Findings clearly stated? NO 10. Impact/value? Yes
Gurevich et al., 2004	Qualitative	No Inclusion/Exclusion criteria mentioned.	Thorough analysis section with themes outlined and quotes supporting considerations.	No study limitations are discussed.	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes

					8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Hauken, et al., 2019	Qualitative	Inclusion criteria specified as those aged between 18-35 and had completed cancer treatment within the previous 5 years.	Thorough analysis section with themes outlined and quotes supporting considerations. At times very difficult to distinguish specific diagnosis related difficulties.	Researchers considered the following research limitations: • No participants were aged between 18-24, so could not observe if the experiences of older TCS occurred in younger TCS, • The time between diagnosis and finishing treatment varied, with no exploration as to how this time period may have influenced research findings.	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Kristjanson et al., 2006	Qualitative	Inclusion criteria stated as: • Older than 16, • Can provide written consent, • No language concerns. Exclusion criteria states was due to recent diagnosis.	Thorough analysis section with themes outlined and quotes supporting considerations. Themes also distinguish experiences felt	No limitations are discussed.	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes

			at different time periods to provide more thorough analysis.		
Saab et al., 2014	Qualitative	Inclusion criteria described as: • Residents of Lebanon with Lebanese nationality, • Aged between 18-50, • Completed TC treatment for a minimum of 3 years, Exclusion criteria included TCS whom did not provide consent to have their interview recorded.	Thorough analysis section with themes outlined and quotes supporting considerations.	Researchers considered the research limitations surrounding qualitative research. Alternative explanations of results provided: • Cultural factors may inhibit full disclosure of experiences, including vulnerabilities,	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes 8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes
Sheppard and Wylie, 2001	Mixed design (quantitative and qualitative)	Inclusion criteria described as: • Aged between 18-40, • Currently in a heterosexual relationship,	Thorough qualitative analysis included, observing themes with some quotes. Key themes were identified and	Researchers considered one study limitation: • Sexual status prior to diagnosis was not explored. Researchers developed a	1. Aims stated? Yes 2. Methodology appropriate? Yes 3. Research design appropriate? Yes 4. Recruitment strategy appropriate? Yes 5. Data collection addresses issue? Yes 6. Reflexivity re relationship? Not discussed 7. Ethical issues discussed? Yes

	- Could complete questionnaires independently or with minimal support. Exclusion criteria described as: - Greater than 5 years after diagnosis, - Current diagnosis or treatment of depression or hypertension, - Previous sexual dysfunction treatment (including medication).	discussed, including distinguishing content between a wife of a TCS to help specify origin of information.	new hypothesis surrounding intimate relationships and confiding in others. No alternative explanations explored.	8. Analysis rigorous? Yes 9. Findings clearly stated? Yes 10. Impact/value? Yes

General Critique

All studies detailed their research aims and qualitative research was appropriate to the aims of understanding the experiences of TC cancer survivors, even when this was alongside survivors of other forms of cancer (e.g., Dobinson et al., 2016).

Low participant numbers challenge the generalisability of the research findings (Morse, 1999). Other criticisms include the inability to eliminate researcher bias (Norris, 1999). These are considered in Carpentier et al., (2010), Dobinson et al., (2016), Fleer et al., (2006), Hauken et al., (2019) and Saab et al., (2014). Only Kristjanson et al., (2006) considered researcher reflexivity, suggesting the other studies did not consider the reflective positions of the interviewers. A limitation of Chapple and McPherson (2004) was the possible attrition of memory in some TCS and acknowledging that ‘masculinity’ may have many forms, which was unaccounted for in their interview schedule. A consideration of the researchers understanding of ‘masculinity’ may have addressed the latter limitation through considering their reflexivity.

Participants

Although some studies achieved good sample sizes for their research aims, it is important to clarify that some participants were not TCS, and thus irrelevant to the aims of this review (e.g., Dobinson et al., 2016; Hauken et al., 2019). These studies involved 3 and 2 TCS participants respectively, limiting the relevance to this review.

All studies utilised a form of purposive sampling, which suggests all research is susceptible to researcher bias (Norris, 1997). Some conscious/unconscious factors may have influenced the researcher’s selection of participants, which may limit the transferability of the results. This may explain why no TCS between the ages of 18-24 were sampled in Hauken et al., (2019), as the researchers may have been biased towards recruiting TCS over this age.

However, clear criteria had been specified regarding inclusion and exclusion criteria for most studies, which would reduce the risk of researcher bias. Some research did not specify inclusion or exclusion criteria (e.g., Chapple & McPherson; 2004; Gurevich et al., 2004). This would suggest these studies were more susceptible to researcher bias than the others whilst also limiting the transferability of the findings. However, the research reviewed covered different countries, including the UK, Australia, Netherlands and Lebanon. This may improve the transferability of the findings, such as cultural influence when outcomes correlate across TCS in different countries.

There were some limitations in the research relating to participants and sampling. For example, in Gurevich et al., (2004) all participants were recruited from a single hospital testing site. This creates further challenges to the generalisability of the findings, as perhaps the experiences of the TCS in this study may be influenced by treatment at the hospital. Another critique is that the average time period since diagnosis was 49.5 months, with a range between 1 – 228. This creates difficulty in associating experiences with particular time periods as research has shown the experiences of TCS can differ over time (Kristjanson et al., 2006). The period of time also indicates the possibility of other influences which may have contributed to the TCS experiences that were not addressed through the interviews (e.g., Hauken et al., 2019).

Kristjanson et al., (2006) also did not seem to identify any limitations of their research. However, the researcher did not specify the ages of the TCS, only that they were all over the age of 16. The age of the TCS may affect their appraisal of their experience, and thus influence their answers at interview. The researchers also found that 12 TCS participants preferred a female interviewer, whilst 20 preferred a male. This seemed to be unaddressed within the interviews, as perhaps some TCS found it more challenging to disclose their experiences to either gender.

Data Analysis

A variety of qualitative analyses were conducted in the studies mentioned, including inductive thematic analysis, grounded theory and thematic decomposition. All studies detailed the process of the analysis except for Kristjanson et al., (2006), where the process was vague. It is worth noting that Fleer et al., (2006) utilised a mixed methods design, which may explain why there was no formal qualitative analysis of the results. Although they interviewed higher numbers of TCS (30) than some other studies in this review, they seemed to draw the fewest qualitative conclusions. Fleer et al., (2006) did not seem to analyse their qualitative results and utilised no interview quotes to support any conclusions. Their analyses appeared to focus almost solely on the quantitative aspects of their research, so only the results from the qualitative interviews were utilised to extract themes from their reported findings.

The majority of studies included quotes to help support their analyses, however at times it appeared difficult to distinguish the experiences of TCS from survivors of other forms of cancer (e.g., Dobinson et al., 2016; Hauken et al., 2019). This challenges the conclusions drawn when relating these to the experiences of TCS. Sheppard and Wylie (2001) distinguished the views of a wife of a TCS which helps to isolate the experience, creating richer outcomes. Kristjanson et al., (2006) also characterised experiences relating to different time periods as part of their research.

This created a more in-depth understanding of how the experiences of TCS could change and develop as the months following treatment continued.

Discussion

This review aimed to explore which aspects of life do TCS describe as being the most impacted following diagnosis and treatment. Qualitative papers observing the experiences of TCS are scarce, thus this review included research that specified TCS within their participants. The research found participants described impacts in various aspects of their lives. These will be discussed in further detail.

Relationships

One key area impacted appears to be relationships. Carpentier and Fortenberry (2010) completed a literature review observing the impact of romantic and sexual relationships in AYA TCS. They found that TCS in committed romantic relationships felt ultimately closer to their partners following the cancer experience. They also found that TCS whom were unpartnered during diagnosis and treatment experienced greater anxiety surrounding future relationships. They concluded that being single during diagnosis increases an individual’s vulnerability that appears to maintain even when successfully engaging in romantic relationships. The results of this review correspond with these findings as it was found that partnered TCS often experienced an increased sense of closeness with partners through the experience (e.g., Chapple & McPherson, 2004; Saab et al., 2014). However, it was also found that some partnered TCS experienced difficulties because of treatment, such as Sheppard and Wylie (2001) reporting one TCS felt that the TC experience resulted in their romantic relationship ending. This review also found that some unpartnered TCS expressed concerns over future relationships, as mentioned in Saab et al., (2014). TCS in

Sheppard and Wylie (2001) even reported an awareness that being single during treatment would have negatively impacted future romantic relationship experiences.

These findings suggest that TC may impact the TCS's relationships. Although being in a committed relationship appears to mitigate some of this, it does not provide a barrier to this impact. Previous research has found that unpartnered TCS have lower perceived levels of social support than partnered, with significantly lower levels of reported self-esteem (Tuinman et al., 2006). This may explain the impact of being in a relationship during treatment, as perhaps there is more social support available to help the TCS manage the experience. This may also explain why some unpartnered TCS in Kristjanson et al., (2006) accepted support without question, and why some TCS in Dobinson et al., (2016) reported unmet needs of wanting to meet with other survivors. This is key when considering the importance of social support in people recovering from cancer (Usta, 2012).

Disclosure

Another impact, related to relationships, was the disclosure of difficulties. Unpartnered TCS appeared to struggle the most with disclosing their TC history to others, especially new romantic partners. These difficulties appeared to surround many aspects of disclosure, such as timing of disclosure (Carpentier et al., 2010), disclosing to family (Saab et al., 2014), and perceived reactions from others being distressing (e.g., Carpentier et al., 2010; Saab et al., 2014). This may be explained using the Social Cognitive Processing Model (SCP) (Lepore, 2001), as different aspects of the client's social environment may affect adjustment to cancer. The SCP also details social constraints experienced by cancer patients (in this instance, TCS) which the TCS may need to manage. The other persons perceived unhelpful, avoidance or critical manner may therefore be managed by non-disclosure, as potentially seen in Saab et al., (2014) and Carpentier et al., (2010). This may explain some of the motivations to non-disclose and may be considered by clinicians when discussing TC with patients, particularly when high levels of social constraints on disclosure have been shown to negatively impact psychological wellbeing in breast cancer risk patients (Schnur et al., 2004).

Physical Self

The physical self appears impacted in TCS, which includes perceptions on physical appearance and functioning. Examples are wanting to conceal the physical loss of a testicle from others (Carpentier et al., 2010) and experiencing fatigue and exhaustion (Saab et al., 2014). Several TCS also perceived their bodies to be ‘damaged’ (Carpentier et al., 2010). Even when the mechanics of sex remain the same following treatment, some TCS experienced body-image concerns including in sexual performance (Gurevich et al., 2004). This displays an evident impact stemming from the physical changes associated with TC treatment and the psychological adjustments that follow, even when the function of the body is retained.

The findings correspond with those of previous research. For example, Rossen et al., (2012) found that body-image was impacted in a sample of 401 TCS. They also found that high levels of erectile dysfunction associated with low body-image appraisal, suggesting the impact of TC on one’s body-image can have direct and indirect effects. These can include erectile dysfunction, sexual performance concerns and negative body-image appraisal.

Research has found that fertility concerns impact male self-perceptions of masculinity (e.g., Gannon et al., 2004). This review corroborated these findings, as TCS were found to experience concerns over their infertility risk in relation to treatment of TC (Saab et al., 2014; Hauken et al., 2019).

Impact on Masculinity

The impact of fertility in relation to masculinity has briefly been discussed above. Saab et al., (2014) also discussed cultural factors/expectations on men in Lebanese culture where fathering a child seems to be a benchmark to attaining masculine adulthood. A sense of masculinity in TCS appeared to be impacted by various aspects of TC treatment. This includes TCS with (Chapple & McPherson, 2004) and without prosthesis where TCS held an insecure sense of masculinity and could involve developing an adapted sense irrespective of the presence of both testicles (Gurevich et al., 2004). Gurevich et al., (2004) also found some TCS linked fertility and masculinity, thus a lack of fertility resulted in a reduced sense of masculinity.

The findings of this review correspond with previous research such as Skoogh et al., (2011), who found feelings of uneasiness or missing the lost testicle to be common amongst TCS. They also found that TS who were not offered a prosthesis experienced higher levels of shame, uneasiness and loss, possibly due to the strong connection men often hold between their testicles and their sense of masculinity (Rieker, 1996).

Fertility

An impact common amongst the research reviewed was fertility, which is understandable considering the function of testicles. This also includes TCS reportedly experiencing little to no support surrounding psychologically managing infertility (Dobinson et al., 2016).

It is important to note the connection between fertility concerns and relationship status. Unpartnered TCS appeared to experience the most impact surrounding fertility concerns (e.g., Sheppard & Wylie, 2001), which the researchers related to the age of the TCS as older (partnered) participants did not seem to experience fertility concerns. This was likely due to them having already fathered children. Thus, it seems unpartnered TCS are most at risk of experiencing this impact.

Sex and Sexuality

Building on from fertility concerns, some TCS described impacts on their sex and sexuality, which includes sexual difficulties both short and long term. Dobinson et al., (2014) described sexual difficulties ranging from communicating with sexual partners, asserting oneself sexually and fear of judgment from others. TCS in Gurevich et al., (2004) described a ruptured sense of sexuality/fertility with one TC struggling to maintain an erection. Sheppard and Wylie (2001) found TCS experienced reduced sexual activity without a reduction in sexual interest, which may suggest psychological factors as opposed to physical. This corresponds with previous research which has found TCS experienced sexual dysfunction even after a few years following completion of treatment (Aria et al., 1997). This also displays a key impact which may be explored qualitatively in future to understand the psychological underpinnings of the concerns.

Clinical Support

The impact of clinical support seemed to be a recurring theme in the research reviewed. The majority of the impacts appear to surround clinicians withholding information or guidance, leading to unmet psychosexual needs (e.g., Dobinson et al., 2016). One TCS in Kristjanson et al., (2006) described being unaware of his infertility until he directly asked radiologists, believing he would not have been informed otherwise. The same research seemed to emphasise the importance of professional tone surrounding TC, and how TCS often became passive and accepting of medical information. When this is considered alongside findings from Chapple and

McPherson (2004), where some clinicians discouraged the insertion of prostheses, this may suggest that clinical support also has an impact that can contribute to the others mentioned in this review.

Positive Impacts

There were some key positive impacts reported by some of the research. This includes an awareness that masculinity, fertility and sex impacts may be short term (e.g., Chapple and McPherson (2004). This may be the result of clinicians provided clear information and guidance, thus improving retention and processing of information. Other positive impacts include a deeper appreciation of life (Hauken et al., 2019), an increase in physical activity, socialising and an improved sense of control of one's life (Kristjanson et al., 2006). Considering the findings of Fleer (2006) where TCS were more likely to disclose experiences to others if experiencing elevated cancer-related stress, a positive social impact may be considered. This has been discussed with partnered TCS (e.g., Sheppard and Wylie, 2001), and Saab et al., (2014) found that some TCS utilised partners, faith and other TCS to cope with TC. This shows the potential positive impact of a social community.

What does this review offer?

This review offers a summary of the various impacts TC can have on a survivor's life. Whilst most of the research was of good quality, it is worth noting that there is a scarcity of accessible exploratory qualitative research observing testicular cancer. This may be due to the possibility that other research has been conducted on the various other forms of cancer, thus assuming the impacts to be similar. Most of the studies utilised quotes to support their conclusions, although this may have been strengthened with clearer methodological guidelines. Considering the research appeared to be from different cultures, the shared impacts display a degree of ecological validity.

Nevertheless, this review has identified various impacts TC has in an individual. These impacts often interact with one another, such as with fertility and masculinity. TC appears to impact the individual both physically and psychologically, challenging their identity and increasing anxiety over the future. Even when treatment is successful, the TCS appears to be impacted in their ability to relate to others and in multiple aspects of their sexual development. However, there are also positive impacts both physically and psychologically gained by some TCS. The subject is clearly complex with interwoven concepts that need to be considered, such as the various forms of masculinity (Buschmeyer and Lengersdorf, 2016) that may also be impacted.

Clinical Implications

Various clinical implications arise from this review regarding future treatment of those diagnosed with TC to minimise negative impacts and promote the positive.

The relationship status of the patient should be taken into consideration, as those who are unpartnered appear to be at the highest risk of not disclosing their difficulties or diagnosis to others. They may also withdraw socially which would further their difficulties and even contribute to further mood challenges (Veale, 2008). This risk is evident even in those with lower levels of cancer-related stress, whom may be at higher risk of non-disclosure of difficulties. Partnered TCS may also experience difficulties in communicating sexual issues to partners and other men. Psychoeducation and referral to support services may reduce these impacts on the patient, as withholding information appears to perpetuate the difficulties. This may also help with TCS experiencing body image issues and concerns over their sense of masculinity. Psychological services may be able to help TCS make sense of their diagnosis, treatment and any new appraisals resultantly made.

Clinical support provided by clinicians should be professional, yet compassionate and sensitive to the client's needs. Information should not be withheld as this can exacerbate difficulties and prolong the negative impacts experienced by TCS. This includes discussions surrounding fertility and fertility concerns, which should be addressed by the treating physician. Research has shown that cancer patients desire transparency and accessibility of clinical staff, which they felt would facilitate their care (Larson, 1984), which further emphasises these suggestions.

Psychological services may support coming to terms with fertility prognoses following treatment to help manage the psychological burden. These services may also help clients identify (if any) positive impacts and seek to strengthen them, such as increased physical activity, sense of closeness to others and stronger romantic relationships. This would adhere to the NHS Long Term Plan (2019) of offering personalised therapeutic options to cancer patients, which may address some of the aforementioned impacts.

Research Implications

The lack of qualitative research exploring the experiences of TCS has been previously acknowledged. Most of the research appears to be quantitative utilising questionnaires. These are subject to various biases and other limitations. They also do not provide fruitful outcomes surrounding the experiences of TCS which can be built on by services and future research.

Research aimed at AYA TCS appears to be even more limited. Considering some of the impacts of TC, these may be more relevant to AYA TCS, particularly as they may be less likely to be in secure, romantic relationships and may hold more anxiety surrounding fertility concerns. AYA TCS will also have experienced diagnosis and treatment at a key stage of their psychosexual identity development, and thus the impact of TC can be observed in greater detail through qualitative means with participants with a younger age range (e.g., 16-25) than other research has focussed on.

Considering the impact of relationships, it may be necessary to focus research also on partners, family members and significant others of TCS. This can provide a more rounded idea of the impacts, particularly as TCS are susceptible to non-disclosure of difficulties. This may have been the case during the qualitative research observed in this review, with only a few studies interviewing partners.

Conclusion

This review has found that there are various impacts of TC that need to be considered by clinicians and researchers. This review has emphasised the complexities of the impacts of TC on individuals. These impacts have been identified as relationships, physical self, sense of masculinity, sexuality, fertility, and clinical support. Although summarised into separate themes, the impacts may interact and perpetuate one another, such as fertility and masculinity. This increases the complexity of care required when treating and supporting TCS.

Although most of the impact is understandably negative, there are also some positive impacts which may be utilised to help the TCS manage the difficulties associated with TC treatment. These include strengthened relationships, an altered sense of masculinity and an increase in positive physical activity. Medical clinicians can focus on the promotion of physical activity to help strengthen this potential impact, whilst psychology can help facilitate strengthening of relationships and the adapted sense of masculinity, including the new appraisals the TCS has made regarding themselves.

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Section B

An Interpretative Phenomenological Analysis of the Psychosexual identity development in adolescent and young adult survivors of testicular cancer.

Word Count: 8,000

Abstract

Background: Qualitative research has explored how some testicular cancer survivors (TCS) experience the psychological impacts of diagnosis and treatment. More research into the impacts of testicular cancer (TC) on adolescent and young adults (AYA) is needed due to the critical period of identity development. The present study aimed to explore how AYA with TC appraise and make sense of their experience and to develop a greater understanding of psychosexual identity development in AYA TCS. **Method**: Eight AYA TCS were interviewed. The results were analysed using Interpretative Phenomenological Analysis. The questions explored the experiences relating to diagnosis and treatment, how it affected their psychosexual identity development (e.g., sexual relationships and self-image) and the meanings attached to the experiences. **Analysis**: Four Group Experiential Themes were developed from the data; 'Dealing with the shock', 'Fear and weight of responsibility', 'those closest to me' and 'sense of change'. **Discussion**: The AYA TCS experiences may result in adoption of traditional masculine traits (e.g., stoicism) or abandonment of traditionally masculine traits (E.g. violence and aggression). AYA TCS also described feelings of insecurity when compared to other men. Psychology input could help manage stoicism and feelings of inferiority when compared to men with two testicles.

An Interpretative Phenomenological Analysis of the Psychosexual identity development in adolescent and young adult survivors of testicular cancer.

Testicular Cancer and Treatments

Research has shown that cancer rates amongst men between the ages of 15-39 has risen by almost 30% in over four decades (Scott et al., 2020), understood to be a result of increased awareness of symptoms, better detection and earlier diagnosis. The same research found that testicular cancer (TC) was the most common cancer diagnosis in adolescent and young adult (AYA) with testicles. Between 2016-2018, TC was the most prevalent form of cancer in AYAs aged between 16-24 (Cancer research UK, 2015). This review will define AYA as those aged between 16-24.

Current medical treatments for TC are centred around three approaches: orchidectomy, (removal of a testicle), chemotherapy and radiotherapy. The prognosis is reported by Cancer Research UK (2022) as 95% survival rates even after five years. Provided the cancer has not spread to lymph nodes or other complications have arisen, Cancer Research UK (2022) described a consistent 95% survival rate after one year.

Testicular Cancer and Impacts

Although no lasting side effects are reported with a single orchidectomy (NHS, 2018), patients are often offered the opportunity to freeze sperm through sperm banking due to potential future fertility concerns. Removing both testicles (double orchidectomy) leaves the patient infertile and will require further treatment, such as prior sperm banking alongside testosterone replacement therapy (NHS, 2018).

Qualitative research has explored how some testicular cancer survivors (TCS) experience the psychological impacts of diagnosis and treatment. For example, Dobinson et al., (2014) described sexual difficulties including communicating with sexual partners, asserting oneself sexually and fear of judgment from others. Carpentier et al., (2010) found TCS perceive their own bodies to be ‘damaged’ following treatment. Fleer (2006) found TCS were not more vulnerable to impaired quality of life, which further displays the psychological impact of diagnosis and treatment. However, more research into the impacts of testicular cancer in AYA populations is needed as research has often focussed on adult TCS.

Testicular Cancer and Psychosexual Development

Testicular cancer (TC) can occur in AYAs who have yet to progress into physical maturation through puberty. AYA’s are at a critical period of identity development, which involves the development of a sexual-self (Biro & Dorn, 2005), starting sexual relationships (Collins & Sroufe, 1999) and general physical sexual maturity. The onset of puberty itself comes with various anxieties, including self-image (Ofer et al., 2013), thus the diagnosis and treatment of testicular cancer (TC) could add further complications as it can give rise to negative self-judgment of appearance and reduced sexual functioning – with the effects continuing years after recovery (Bellizzi et al., 2012, Wettergren et al., 2017). TC treatment often involves surgery to remove a testicle. This will understandably have an impact on the individual, regardless of their age or physical health (Skoogh et al., 2011) but especially AYA patients undergoing puberty.

Current Psychological Treatment Recommendations

Current psychological treatment recommendations for AYA's with cancer often focus on improving peer support and maintaining the AYA’s sense of identity (e.g., Park & Rosenstein, 2015). However, there are other challenges the individuals can experience that can go unaddressed with current approaches. These challenges include gender identity (or self-perceived gender, regardless of birth sex), sexual functioning, relationship support and sexuality (Dobinson et al., 2016). Dobinson et al. (2016) developed a grounded theory of the psychosexual needs of TCS aged between 15 - 35 and found that several needs went unmet. This included identity conflict, specifically regarding age incongruity between their self-perceived and chronological age, changes in intimate relationships, disclosure to others and reconciling identity conflict.

A small amount of research has emphasised the needs of AYA (E.g., Dobinson et al., 2016) using grounded theory, however this was with a broad range of cancer survivors. There is a lack of understanding and sense making of the lived experience of AYA TCS. Although recommendations for medical support have been made (e.g., Moore et al., 2013), including advising more education on sexuality issues, the lack of research detailing psychological needs is apparent. Kelly (2013) recommended an increased awareness in addressing age-appropriate psychosexual support age especially as testicular cancer and its treatments impact biological factors and the individual’s sense of identity and sexuality.

Gender Development

Gender has been described as socially and psychologically constructed and involves understanding societal roles, characteristics, behaviours, and the social norms regarded as ‘suitable’ for the determined gender (Ryan, 2007). This suggests that the development of conceptual gender is complex, with previous notions of binary gendered development deemed outdated (Hanssen, 2017). It is yet unclear if TC has an impact on gender development, particularly when diagnosed as an AYA.

Masculinity Development in AYAs

Pappas (2019) described a ‘harmful’ construct of ‘traditional’ masculinity as including dominance, aggression, competitiveness and stoicism, which may also relate to bigoted views and behaviours, such as misogynistic or harassing (De Boise, 2019). A more ‘general’ masculine construct is defined by Pleck et al., (1993) as culturally specific, with consideration to how much individuals endorse and internalise these cultural expectations on masculinity – thus, unbound by specific criterion.

The development of the masculine identity can begin during adolescence, with individuals appreciating masculinity can change throughout their lifetime as their body changes (Connell & Connell, 2000). Research has shown the importance of the physical body when constructing a sense of masculinity during adolescence (Mora, 2012), thus it seems any changes to the body during this time may also impact one’s sense of masculinity.

However, the removal of a testicle through orchidectomy has not always resulted in an impact on one’s sense of masculinity. Marilyn et al., (1995) found that following orchidectomy, sex-role and quality of life remained intact, however the loss of sexual function was reported to be psychologically distressing. This suggests one’s sense of masculinity may still be impacted through diagnosis and treatment of TC, but it may be unrelated to physical alterations in the body. It also suggests there may be other factors not previously considered by quantitative research regarding how the loss/removal of a testicle or other changes in bodily function may impact the sense of masculinity, if at all.

More recent research has emphasised the importance of close interpersonal relationships in shaping an AYA's sense of masculinity (Rogers et al., 2021). The researchers suggest that the physical body may provide an indirect influence on one's sense of masculinity, particularly where AYA's who are smaller in frame may struggle more with their sense of identity development.

There are also societal/environmental contributors to one's sense of psychosexual identity development, particularly when features such as a disposition to engage in 'high risk' activities that may result in injury are higher in those who hold a masculine identity that is more 'traditional' (Javouey et al., 2006). As AYA's are found to be more likely than other age groups to engage in high-risk behaviours (Spring et al., 2012), this provides another example of how psychosexual development of AYAs may be prone to influence from societal factors.

Rationale for the study

The exploration of the psychosexual impacts of testicular cancer is essential in understanding the nuances involved in this critical period of an AYAs life-stage. This can also allow insights into the importance of medical and psychological care in mitigating potential consequences to the development of psychosexual identity or facilitate potential beneficial outcomes (if any).

The present study aimed to gain an in-depth understanding of how AYA with TC appraise and make sense of their experience and to develop a greater understanding of psychosexual identity development in AYA TCS. This includes how they make sense of their diagnosis, treatments, and other impacts such as with close and romantic relationships.

Aim and Research questions

The following research questions will be explored:

1. How do AYA TCS experience and make sense of their diagnosis and treatment of testicular cancer?

2. How do AYA TCS describe the impact of having testicular cancer on their psychosexual identity and relationships with others?

3. How do AYA perceive the support they received following their diagnosis and treatment?

This project is therefore grounded in certain NHS Values, including ‘Working Together for Patients’ and ‘Commitment to Quality of Care’. This can also help clinicians work with AYA testicular Cancer sufferers with more compassion, improving their lives and enhancing the positive clinical outcomes in their presentations (e.g., reducing need for further psychological or medical input). This will help develop protocols and recommendations for medical and psychological input in the future and look to address these unmet needs as corroborated by other studies using grounded theory (e.g., Dobinson et al. ,2016).

Method

Design

The study used a qualitative design involving an interpretative phenomenological analysis (IPA) (Smith et al., 2009) of semi structured interviews. Due to the limited research surrounding the experiences of AYA TCS including psychosexual identity development, a qualitative approach was considered the most appropriate as it allowed for an exploration of the phenomena through gathering rich information from participants.

IPA aims to observe individuals' experiences and perceptions relating to often transformative events - in this instance, diagnosis and treatment of TC. IPA is also well-placed to explore identity changes following these transformative events (Smith et al., 2022). Through semi-structured interviews, a detailed exploration of how TCS made sense of their experiences and the meanings derived from them can be recorded (Osborne & Smith, 2008). IPA was preferred over other qualitative approaches such as Grounded Theory (Charmaz, 2008) which aims to take a more explanatory approach. This research aims to explore the experiences and meaning making of a homogenous sample of TCS. IPA also adopts a 'double hermeneutic' process (Smith et al., 2009) whereby the researcher's role in interpretation of the participant's experience is considered within the research itself. Following the TCS' interpretation of their experience, the researcher's interpretation of the TCS account occurs.

Expert by Experience Involvement

An expert by experience (EBE) was consulted in this project and they agreed to support the research at various stages. The EBE was an AYA TCS and represented the type of participants recruited in the research, thus their involvement was essential to ensure the research was as robust as possible. The EBE was involved in the construction of the semi-structured interview schedule and in checking the credibility of the analysis by the lead researcher (Smith et al., 2022). The EBE's involvement with the interview schedule included adapting present questions to provide a richer, more accurate account of the TCS experience. All suggestions made by the EBE were discussed in the research team before being implemented formally into the research.

Recruitment

The participants were purposively sampled from a London NHS hospital's Adolescent Oncology department. The consultant was able to assess and verify the potential participants capacity to consent to research prior to their details being forwarded to the lead researcher.

The details of potential participants, who had previously consented to engage in TC-related research, were emailed to the lead researcher who then made contact by telephone and asked if they wanted to optionally participate. The phone call involved briefly describing how the research involved interviewing TCS about their experiences of diagnosis and treatment. Potential participants were able to ask questions and if they agreed to take part or wanted to read more about the study, were emailed an information sheet (Appendix B) and a consent form (Appendix C). Before the phone call ended, an appointment was made with the participant to engage in the recorded interview over Zoom and they were informed that they needed to send the signed consent form back before the appointment.

Four participants verbally agreed to take part in the research and were sent the corresponding emails. The participants then cut contact with the researchers by not responding to phone calls or emails any longer. Thus, no formal reason for refusal to engage was obtained.

Inclusion Criteria

The AYA TCS all met the following inclusion criteria:

- Aged between 16-25,
- Diagnosed with testicular cancer between the ages of 14 and 19, potentially recruited as young adult or teenage survivors,
- Diagnosed and treated in the UK,

- Who have completed treatment for testicular cancer,
- Their participation in the interview could be facilitated without an interpreter.

An upper age limit of 25 years old was used to keep the participant sample homogenous, but also as this is the age limit of the service within the hospital. It also fit in with the definition of AYA used in this review.

Participants

Smaller sample sizes are suggested for IPA due to the qualitative nature of the research (Smith et al., 2009). Traditionally, IPA utilised homogenous samples to determine common themes, thus a rich analysis of the experiences of this sample would provide more valid results regarding the research aim (Pietkiewicz and Smith, 2014). IPA recommendations for sample size (Pietkiewicz and Smith, 2014) and the requirements for doctoral level research led to a recruitment target of 8-10 participants.

There were difficulties with eliciting approval from the hospital recruitment site – owing to COVID-19 related research approval delays. This affected the number of participants that could be recruited and interviewed within the timeframe for the project and resulted in eight AYA TCS participating in the study. The lead researcher may have recruited more but felt that this would address the research aims and was anxious to spend time recruiting further (explored in the bracketing interview).

Table 1 displays a summary of the participant demographic data.

Table 1: Participant Demographic Information.

Pseudonyms	Age	Ethnicity	Diagnosis	Age at diagnosis	Treatment Length

Andrew	18	British	Testicular/Germline Tumour	15	< a month
David	25	European	Testicular Seminoma	19	< a month
Derek	19	British	Stage 2 testicular cancer	14	6-8 months
Henry	22	British	Cryptorchidism Testicular cancer	17	8-12 months
Richter	19	British	Testicular cancer	14	4-6 months
Julius	22	European	Testicular cancer	16	1-3 months
Mish	19	British	Testicular cancer	15	< a month
Roger	17	British	Testicular Germ cell Cancer	16	>12 months

All participants were unpartnered at the time of interview and described ‘extensive’ familial involvement in their treatment and support both during and post-treatment. They all described developing an expertise on TC diagnosis and treatment following their own diagnosis – which was not present prior to their experience.

Interview Schedule

The semi-structured interview schedule can be seen in Appendix D. The questions were designed to help the TCS explore their experiences relating to diagnosis and treatment, how it affected their psychosexual identity development (e.g., sexual relationships and self-image) and the meanings attached to the experiences.

The interview started by asking the TCs what came to mind when they saw the research and what motivated them to take part, before moving on to their experience of diagnosis, treatment, support offered/not offered and their perceptions of themselves. The questions also helped to explore how participants perceived the various potential impacts and any changes the TCS experienced following diagnosis and treatment. TCS were asked if they were ok to answer questions surrounding sexual experiences. The lead researcher was initially anxious to ask these questions due to preconceptions of teenagers discussing sex with an unknown professional, which was discussed in the bracketing interview in more detail. All participants agreed to answer these questions.

Ethical Considerations

The present research attained initial research proposal approval from the university (Appendix E), followed by NHS research ethics committee review approval (Appendix F) and Research and Development (RND) approval from UCLH for the purposes of participant recruitment (Appendix G).

All participants provided informed consent to taking part in the interview and having the interview audio recorded for transcription purposes. Participants were also made aware that if certain questions were too challenging to answer then they were under no obligation to do so and that they held a right to withdraw consent to engage in the research at any time.

The potentially distressing nature of the experiences indicated a possible risk of the interview becoming highly emotive. The researcher was attentive to the emotional reaction of the participants and if it became clear a participant had nothing else to add to their answer then the researcher moved on to the next question. Participants were offered opportunities to take a break and could choose to end the interview if they felt overwhelmed. If it was clear that the participant was significantly distressed, the researcher planned to speak about how and where they could obtain psychological support after interview, including signposting to appropriate services.

Participants were informed prior to the interview that any information, transcript and their engagement in the interview would be confidential. Participants were also informed that if there was an immediate risk of harm to self, others, or from others, then there was an obligation to break this confidentiality to the relevant services. No risk issues arose during the interviews.

Procedure

Following the participant expressing an interest in engaging in the research, a Zoom appointment was arranged. The participants had the opportunity between the initial contact and the arranged appointment to read the information sheet emailed to them and sign the consent form. Participants also had the opportunity to sign and send the consent form during the zoom chat should they have any more questions or to clarify what participation would involve. Following receipt of the consent form, the recorded semi-structured interview began. These took place over Zoom in a location where the participant (and researcher) could speak privately for up to 60 minutes. The interview length ranged between 25 – 60 minutes depending on the responses to questions, speed of speech and level of detail the participant could divulge. All participants disclosed feeling happy to take part and engaged seemingly without distress.

Data Analysis

The data analysis was structured utilising Smith et al.'s (2022) recommendations. Interviews were transcribed by the lead researcher following completion, who then immersed themselves in the transcript through reading whilst simultaneously listening to the audio. Transcripts were read twice in this manner before Exploratory Notes (EN) were made, which were descriptive, linguistic or more analytical initial interpretations (an example is seen in Appendix H). ENs were then grouped according to connections identified by the lead researcher. These formed Experiential Statements (ES), or concepts more relevant to psychological constructs

(Smith et al., 2022) (An example is seen in Appendix I). This was done individually for all transcripts, developing ‘Personal Experiential Themes’ (PET) from the ES (An example is seen in Appendix J). The researcher then determined Group Experiential Themes (GET) that seemed to apply to the AYA TCS, along with the subthemes that are encompassed by the GET (Smith et al., 2022) (An example is seen in Appendix K). Some PETs were regrouped, reconceptualised, or left out so that the analysis could capture as broad a picture of the experience. This paper will therefore focus on the GETS and the encompassed subthemes.

Quality Assurance

The lead researcher took part in a bracketing interview with a trainee colleague prior to the first participant interview. The aims of the bracketing interview are to identify and consider the beliefs and knowledge of the lead researcher conducting the interviews so that these can be benchmarked before data-analysis occurs (Carpenter, 2007). The bracketing interview involved exploring the lead researchers’ views, assumptions and beliefs surrounding TC, treatment, identity development between the age of 14-19, psychological and physical impacts, and these were discussed in supervision to consider any potential influence on the research process (Appendix L). A reflective diary was also kept by the lead researcher at every stage of the research (Appendix M).

Theme development credibility was discussed with the EBE and then with two research supervisors with extensive research and cancer-related research experience to verify the credibility of the developing themes (Elliot et al., 1999).

Results

The findings were organised in to four GETs and 11 sub-Themes (Table 2).

Table 2: Overview of Group Experiential Themes (GETS) and Sub-Themes.

Group Experiential Theme	**Sub-Themes**
Dealing with the shock	Detaching emotionally
	Adoption of a pragmatic approach
	'I don't want to hear about that': Avoidance
Fear and weight of responsibility	Deferring responsibility to clinicians
	Decisions surrounding prosthesis
	The anxiety of others
Those closest to me	Worries around future romantic partners
	Strengthening personal relationships
Sense of change	Inspiration
	Personality change
	Angry at self

Dealing With the Shock

This GET incorporated the way the participants managed the shock they experienced during diagnosis and treatment. There was an impression from each participant that many aspects of their experience were shocking in different ways. Although some participants described already 'knowing' about their diagnosis before medical confirmation, many still described feeling stressed about what could happen. Many strategies seemed to be utilised by the participants, all with the aim of lessening the shock and stress of the situation.

Detaching Emotionally

Almost all participants described either ignoring or ‘switching off’ emotions during initial diagnosis to help manage the shock. There was a sense that this may have helped facilitate daily activities or a return to ‘normality’:

‘*I just ignored my emotions and carried on with my day to day…’* (Derek)

There also seemed to be a sense that feeling these emotions was not an option. David expressed a pull towards thinking emotionally, but an awareness that this may have inhibited his ability to consider his prognosis:

‘I think for me it would have made me think too much about the emotional side of things and that meant I wouldn't have thought straight about the treatments and the solutions…’ (David)

David also seemed to allude to a lack of control if he were to focus on emotions too much, thus detaching emotionally may help regain ‘control’. The belief that emotions held a restrictive or inhibitory quality seemed prevalent in many participants. This is also echoed by Andrew, who alludes to despising the emotions he felt following diagnosis with a sense that experiencing them would result in a lack of ‘control’ of the situation:

‘*You feel kind of vulnerable and I hate that feeling, I despise that feeling, I like to be in control…*’ (Julius)

Adoption Of Pragmatic Approach

Most participants appeared to focus on treatments, solutions and recovery throughout their experience. This seemed related to treatment decisions and a shift of focus away from worrying, or other emotions.

‘I just wanted to get on with my life, I just focussed on beating it and then ended up coming out the other side winning.’ (Roger)

Roger seemed to describe how a pragmatic approach helped him regain a sense of normality in his life, and a sense that there is some causal relationship between thinking pragmatically and overcoming TC. This is echoed by David, who seemed to describe how a pragmatic approach, devoid of emotion, helped the situation gain clarity and thus, alleviate some of the shock and stress.

'…there's no point breaking down and being all emotional about it, this is the situation - you move on, you think about the solution.' (David)

There was also a sense of downplaying the severity of TC, which may have been a result of emotional suppression and the adoption of a pragmatic approach offsetting the shock and stress.

'Brain tumours are one of the most complex types of tumours and complex regions to operate on in general… I came out of my little bubble and thought there are a lot bigger issues out here. (Andrew)

It seems Andrew is describing how a pragmatic focus on facts, devoid of emotion, helped him to appreciate a level of 'simplicity' in his diagnosis and treatment. He also seemed to manage the shock and stress of diagnosis and treatment by considering his TC as less severe and easier to operate on than brain tumours.

'I don't want to hear about that'

Some participants would actively avoid various aspects of their experience at the time, in particular disclosure to others, seemingly to simulate a return to normality.

'I would just go out with my friends and chill. They wouldn't know anything, but I just acted like things were completely normal and would just chill.' (Henry)

Henry's friends seemed to represent normality, and thus a longing to return to this. It seemed that Henry was able to relax when with his friends, and that their ignorance to his situation may have helped to avoid the shock and stress associated with it, even if temporarily.

At other times, Henry seemed to avoid the use of certain words, such as ‘sperm’.

‘My productivity as well. It was reduced, but that's why I had to do the banking…. but it did reduce but not massively. But it was still enough.’ (Henry)

It seemed that Henry may have been avoiding using the word, but the fact he was doing so may have suggested the shock of his situation was driving some behaviours. In short, the shock was unavoidable, but what could be avoided was perpetuators or reminders of reality. Avoidance of reality may serve to provide short term relief, as Henry described before he had received diagnosis.

‘Well, it ended up going massive... I randomly saw one of them was large… So, I was very, very embarrassed about it. And I thought, nah, this isn't right. But I didn't speak out on that. I just let it be and I kept to myself. And they go larger and larger and painful....’ (Henry)

Henry not only avoided seeking help when he noticed something was wrong, he also avoided using the word ‘testicle’ whilst recounting his experience. It seems the avoidance, possibly like the pragmatic adoption, may persist after treatment has ended.

A consequence of the avoidance may also be that some participants’ reality is impacted, such as with David who described a difficulty in saying the word ‘cancer’.

‘Since telling people I have found it quite hard to say the word cancer … and because I physically can't say the word…’ (David)

It seemed David was unsure as to why he was unable to say the word, describing his difficulty as more than psychological but also a physical inability that is outside of his awareness.

Fear And Weight of Responsibility

Participants often described a fear of certain responsibilities during their experience. This ranged from an awareness of their own intellectual limitations surrounding treatment decisions, to even whom to disclose to. At times, the fear could be so great that the participant would actively refuse to hear any information. Some participants seemed to rely on others to make decisions surrounding their care and even disclosure, possibly to reduce their sense of uncertainty as the professionals ‘know better’. The weight of the responsibility also seemed anxiety inducing in participants, as such this would facilitate deferral to health professionals.

Deferring Responsibility to Clinicians

Some participants seemed to rely on the clinicians when it came to making the best treatment decisions. There was a sense of complacency, almost a submission to the will of another.

‘It was very much ‘we will go with whatever the consultant thinks is the best option for my health’ going forward.’ (David)

David seemed to acknowledge that the situation was willingly out of his control, and that he had relied on the consultant to make the best choices in his interest. Others seemed to feel clinicians were responsible for whether the participant needed psychological support.

‘I’m pretty sure she could tell I wasn’t in psychological distress or anything... So maybe that’s why they decided not to - you know - refer me to a therapist.’ (Mish)

Although there was a deferral of responsibility, there was also a sense of uncertainty over some of the clinical decisions. Mish described an idea as to why he was not referred for psychological input but is uncertain. Nevertheless, he described an attempt to make sense of the consultant's ("she") decision, even after deferring responsibility.

However, for some participants deferral led to an increased sense of certainty. *'I immediately would just cut it off and say: 'my only choice is what you decide'… I'm 16 I'm not going to give you advice on what treatment I should have.'* (Julius)

Julius seemed aware of his age limitations and lack of knowledge, which seemed to increase the anxiety of hearing the different treatment options. As such he would refuse to hear the options, and defer all responsibility to the medical team, citing his age as the reason he should not be involved in decision making.

Decisions Surrounding Prosthesis

Some participants felt that the responsibility over whether to have a prosthetic implanted remained with others, even if this contrasted the participant's desire. *'No, I didn't have a choice. My parents were the main choosers because I was 15…I would want a fake one actually. Why not? Actually, if I was given the chance, I would have one.'* (Richter)

Richter appears to be describing how his parents held the responsibility around choosing whether to have a prosthetic implanted. He alludes to his age when discussing why he did not get a choice, but there is also a sense of regret over the decision his parents had made for him. This sense of regret is also echoed by Henry: '*But the basis on why I wanted the prosthetic. Is basically because I'm very insecure… I just wasn't offered the prosthetic at the time'*

Here Henry seems to describe decisions surrounding prosthesis remaining with clinicians, however this responsibility was not deferred from Henry. Henry expressed wanting the prosthesis at the time, feeling it would help manage his distress, but he was not offered it.

The Anxiety of Others

Although responsibility has been discussed in relation to others, the participants all seemed to experience the weight of feeling responsible for the emotional experience of close others. This involved a sense of feeling a causal relationship to how others feel, and a sense of taking on a reassuring role to others, which at times seemed burdensome.

'Even though I knew I was going to be fine, they weren't really emotionally there… they were really distressed by it, and I was more supporting them, and they did support me but at certain times' (Mish)

Mish seemed to be describing an awareness of the situation, but that others (in this instance, his parents) were 'not there'. There was a sense of differing levels of awareness, and thus the role of support was adopted by Mish to get his parents to where he was emotionally.

However, some participants described experiencing positive benefits to taking on a reassuring role.

'…but it was nice telling people and reassuring them, it felt ok but as a whole.' (Andrew)

It seems Andrew did not feel the same as Nish, however the reference of 'as a whole' creates a sense that ultimately it was pleasant, but there were aspects of the role that may have been burdensome. There is a sense of the ends justifying the means. Many participants also described a sense of not wanting to burden others, expressing concern that their experience was causing others distress.

‘Why should I trouble these individuals with my own worries? I'm sure they have enough of their own… I don't need to make a big deal out of it.’ (Andrew)

It seems for Andrew, he was aware that his experience would cause distress to others, and there is a sense of guilt in doing this. The idea that adding more stress to an individual, encumbering them with the participants distress would make the situation a ‘big deal.’

Those Closest to Me

Separate from the fear and weight of responsibility is the GET of ‘those closest to me’ and the surrounding impacts. This included relationship changes or perceived difficulties in the future.

Worries Around Future Romantic Partners

Some participants felt that their experience suggested that they were inferior to other men in the eyes of others, with particular focus on future sexual partners.

‘*Well, there are other boys out there with two testicles, so why would anyone want me with only one?*’ (Richter)

Richter seems to be alluding to a sense of inferiority due to his experience. The fact that he has one testicle suggests he is less desirable than people with two testicles. This sense of difference contributes to almost concluding that another person could not want Richter when they could have something ‘better.’ This is exacerbated when Richter describes feeling inferior to other men:

‘*I feel different to everyone else now. I feel like I'm cut in half. If you get what I'm saying.’*

Having one testicle seemed to be understood by Richter as meaning he is half as valuable as men with two testicles. There is also a sense of feeling alone in this, as he references 'everyone else'. This sense of abnormality is shared in other participants, with a perception that they are no longer 'normal.'

'A lot more awkward, definitely… But it's just the awkwardness of how you're not normal, basically.' (Henry)

Strengthening Personal Relationships

Participants also described a strengthening of relationships that they perceived were 'close' prior to their experience. This strengthening also related to familial relationships with one-another (i.e., not towards the participant).

'It brought all sides of my family together, even if they didn't like each other, because they all wanted to be there for me and help me no matter what.' (Roger)

There seemed a sense of reparation of relationships in Roger's account, describing a unification of all those with the same goal. This is echoed by Andrew:

'*These are friends that I still am in touch with to this day of course these are lifelong connections*'

Andrew seemed to allude to a strengthening of already present relationships, and a desire to maintain these interactions in the long term. This pattern was similar in other participants:

'*I only really told two of my closest friends and they were supportive, the relationship grew stronger'* (Mish)

It seems like Mish was selective with whom he disclosed his experience to, however the relationships of those he disclosed to strengthened, with the idea of growth following the new development.

Sense Of Change

All participants described feeling changed or at a stage of transformation. This ranged from positive, negative changes, and some shifts in personality. All seemed to attribute these changes to key aspects of their experience, such as diagnosis, treatment or their perceived reactions from others. Every participant spoke about how various aspects of TC contributed to their sense of identity.

Inspiration

A few participants described how their experience of diagnosis and treatment contributed to their desire to work in medically related fields. One described how the experience had contributed to their sense of purpose to become a doctor.

'I want to get into medicine as well so … I was someone who had a story now, who had a much stronger defined purpose, and this is something that really did impact my self-respect' (Andrew)

Andrew seemed to describe drawing inspiration from his experience, which contributes to some aspects of his sense of self. The sense of transformation comes from this idea that he was 'someone who had a story now,' which suggests Andrew's understanding was that he did not previously. The inspiration is echoed in other participants, such as David, who described associating his experience with his career choice:

'*If I didn't have it I maybe I wouldn't be a doctor today'*

It seems David's understanding of his experience was that it provided the inspiration to pursue a medical career, and a perception that without the experience he may have been in a separate career.

Personality Change

A few participants described a shift in personality following their experience. This particularly surrounded maturing emotionally.

‘I used to get in lots of fights as well, and after that I completely changed. I haven’t gotten into a fight ever since then’ (Mish)

Mish seemed to describe a change in aggression and temperament following their experience. This change of getting into lots of fights to suddenly none at all has an absolute quality to it, in that Mish understands that a part of him has changed ‘completely’. This is echoed in Roger’s interview:

‘*I was just, always being disrespectful and like, being a rude person to parents and siblings, and like, just being very aggressive and everything… Yeah it’s changed a lot’* (Roger)

Roger appears to attribute his reduction in aggression to his experience also. There is a sense of identity change, as Roger referred to himself as ‘a rude person’ prior to his TC experience. Both these accounts allude to a partial transformation, with Mish later detailing more about the change:

‘And it definitely helped me mature a lot… the next year when I went on holiday they were like ‘who are you? Where’s MISH gone?’ (Mish)

It seems Mish associates his experience with a change in personality so drastic, that he became unrecognisable.

Angry At Self

Many participants described a sense of feeling angry at themselves for their diagnosis. This is in contrast to the positive transformations described above, but instead seemed to focus on feelings of blame and shame.

‘I used to drink a lot of Fanta… After being diagnosed, I just quit Fanta altogether. In the way I blamed Fanta, fizzy drinks in general.’ (Derek)

It seemed that Derek understood soft drinks (Fanta in particular) as being responsible for his TC. This suggests that Derek made sense of his diagnosis as a result of his lifestyle choices, and the abandoning of soft drinks in this instance seemed to represent a desire to never return to the experience. In some participants, this anger is turned inwardly:

'…they supported me in the way to try and make me feel more realistic, because sometimes I hate myself over this...' (Richter)

Richter seemed to hate himself over the fact he was diagnosed and treated for TC. This anger aimed inwardly appeared to be managed through the use of others, suggesting a self-soothing approach would be fruitless. The sense of blaming himself is acknowledged as being 'unrealistic,' however Richter described an awareness of this and a sense that the anger is still aimed inwardly.

Discussion

This review aimed to explore the psychosexual identity development of AYA TCS. It has provided initial research exploring the challenges AYA TCS report following diagnosis and treatment through a developmental focus, which supports research focussed on adult survivors. The GETs that emerged were 'Dealing with the shock', 'Fear and weight of responsibility', 'Those closest to me' and 'Sense of change'. The findings are discussed with regards to the aims and wider literature.

Dealing With the Diagnosis

Participants seemed to deal with the initial shock of a diagnosis by seemingly detaching emotionally and adopting a pragmatic approach. It seemed the meaning participants made of their emotions were that they were 'inhibitory' to their physical recovery. This relays a sense that participants were anxious that their shock and stress would impair their ability to manage the situation, which seemed to result in the deferral of treatment responsibility to the medical teams. Recent research has shown that the deferral of treatment decisions is prevalent in adult prostate-cancer patients

(Pan et al., 2022), which resonates with the finding of this study that this may also occur in AYA patients. It has also been found that the traumatic nature of diagnosis evokes emotional suppression in patients (Arteaga Perez, 2020), where the avoidance of expressing emotion in front of close others is meant to preserve relationships. This suggests that the emotional detachment and pragmatic adoption may have also served other purposes, particularly as participants in this study seemed to adopt a reassuring role to others and noted a strengthening of personal relationships.

It could also be argued that distressing emotions could be suppressed by individuals as a defence mechanism, originally described by Freud, to defend against the trauma (Traetta and Doronzo, 2022). This would suggest that the participants engaged in these processes as a means of defending themselves from the trauma of a cancer diagnosis and the associated stigma of cancer. However, Palmieri et al., (2022) found that these defence mechanisms may serve an emotional regulation purpose, which the findings of this research may support. The participants may have been adopting the pragmatic approach as short-term emotional management, postponing their emotions until they have overcome the treatment (Wilkinson et al., 2011). This may also explain the personality changes experienced where participants (Mish and Roger) described a lessened temperament, where they possibly never returned to the distressing emotions. This may also explain the reassuring role participants took with others, to postpone the stress of others to help the participant manage their immediate emotions.

Gender Development

Considering several participants who did not receive a prosthesis described a sense of inferiority when compared to other men with two testicles, this could suggest that the inclusion of a prosthesis may be key to managing the developmental challenges of these AYA TCS. This is particularly important for the AYA TCS interviewed whom described feeling different to others or no longer ‘normal.’ Similar findings have been reported in other studies, where TCS described feeling like ‘damaged goods’ (Carpentier et al., 2010). These concerns appeared to contribute to anxiety surrounding perception from romantic partners and a desire to conceal their ‘missing testicle.’ This insecurity surrounding their bodies and perception from others contributed to their anxiety surrounding future romantic relationships and likely contributed to anger they felt at themselves.

Masculinity in AYA TCS

The findings of this research also support Marilyn et al. (1995), who found that sex-role and quality of life remained intact following orchidectomy, but a loss of sexual functioning was particularly distressing. Participants in this research reported varying degrees of sexual impact following diagnosis and treatment, with some describing feeling insecure and inferior to men with two testicles whilst others described no negative sexual impacts. Some participants did report temporary reduced sexual interest following orchidectomy but seemed able to contextualise this as they were undergoing chemotherapy at the time, which seemed to reduce the negative impact of this change.

No participants explicitly mentioned concerns surrounding masculinity in this research, however, Mish and Roger did describe a shift away from characteristics associated with ‘traditional’ masculinity, namely reduced aggression and violent behaviours. This would suggest that their experience facilitated a shift away from more harmful views of masculinity, possibly reducing their endorsement and internalisation of the belief that this is what masculinity involved. This shift away from ‘high risk’ activities associated with the masculine identity (Javouey et al., 2016) may also suggest TC contributed to the development of a masculine identity that is less ‘harmful’.

It is worth noting that various participants may also be argued to have displayed ‘stoicism’ through their emotional detachment. This may inversely therefore suggest that TC indirectly facilitated their adoption of these harmful characteristics, thus the adoption of more ‘traditional’ masculinity. However, stoicism may have been adopted functionally to protect from the emotional impact of diagnosis and treatment. Thus, stoicism may have provided emotionally and psychologically protective benefits to the TCS (Vaillant, 1976).

These results are in line with Connell and Connell (2000) who found that masculinity may change throughout a lifetime as bodies change, as the participants may have reduced or increased ‘traditional’ masculinity traits because of physical changes through orchidectomy. This may also support Mora (2012) as the physical body displayed importance when constructing a sense of masculinity during adolescence. However, it is yet unclear if this is directly related to the body change through orchidectomy, as not all participants described adopting ‘traditional’ masculinity traits.

No participants engaged in psychological support, with various explanations as to why emerging. Some detailed how they did not feel they needed it at the time, others described how this was not offered by medical staff – with the belief that medical staff felt the AYA was ‘mentally fine’, and others felt this was due to an inability to relate to others who were not AYA TCS. This may also be explained by the adoption of a ‘stoic’ attitude, possibly influenced by medical staff through a lack of offering psychological support, which has been shown to have an impact on stoic attitudes (McAteer & Gillanders, 2019).

Surrounding the experience of support, many participants described positive familial and close-other support at the time of diagnosis and treatment. All described a strengthening of close relationships where the other displayed what the AYA TCS perceived as ‘genuine support’ and care. All participants described a sense of close family connection following diagnosis and treatment, describing immediate family as key support mechanisms. This supports Rogers et al., (2021) in that close interpersonal relationships may have contributed to shaping the AYA’s sense of masculinity. Some participants may have been influenced by family, whom through their own distress did not desire to speak about the experience with the participant, thus influencing the adoption of a stoic attitude. However, the stoicism observed may indicate avoidant attachment styles, with research showing that these individuals may suppress negative emotions and avoid seeking support (Kotler et al., 1994). As some participants in the present research displayed these characteristics, avoidant attachment may also explain the stoicism and lack of support seeking observed.

Limitations

A strength of this research is the time taken to create and verify the interview schedule with the EBE, which resulted in research with more ecological validity. The British Psychological Society stresses the importance of expertise when carrying out qualitative research, emphasising that this improves the quality of the research and findings (BPS, 2022).

It is worth noting a limitation of the present research in that the participants were recruited from one NHS site, where all participants held positive experiences of their interactions with said NHS site. Perhaps other sites or participants who did not have as positive an engagement may have experienced more impairments in their psychosexual developments?

Another limitation is that participants may have spoken positively of their experience through a sense of demand characteristics – or a belief that the lead researcher worked within the NHS site and thus they did not feel able to directly criticise their experience of care. This may have been contributed to feelings of embarrassment talking about intimate difficulties with a researcher whom they did not know previously. This would limit the validity of the research as participants may have felt coerced in to answering in a specific way, as opposed to the truth.

Clinical Implications

The findings of this research support Kelly et al., (2013), who found that psychosexual needs including identity conflict and disclosure were some of the unmet needs of AYA TCS. The findings also support Hart et al., (2021) who found that AYA cancer survivors were unsure what to do when confronted with symptoms and later lacked knowledge of their treatment options. The present study also found that psychological input could be useful, such as with the adoption of stoic attitudes. It is important to note that no participants in this study engaged in psychological therapy. Psychological input and support groups may help identify these unmet needs and address appropriately. The mechanisms for this may vary dependant on service – as the ethics of 'enforcing' psychological assessments on patients may arise.

NICE guidelines (2004) recommend psychological input based on the level of distress experienced by cancer patients, however this study has identified other facets that may warrant psychological input, such as the adoption of stoicism or the inability to say some words. The same guidelines acknowledge that psychological symptoms are often missed by medical staff, resulting in patients who may benefit from psychology input missing out. A recommendation is that psychologists can be more readily involved in identifying the adoption of concerning traits, such as stoicism, and provide an opportunity to discuss decisions being made on their behalf – to manage any distress surrounding these decisions.

Another important clinical implication is the prosthesis. More specifically, how this is communicated to the participant. Considering the possibility that the presence of the prosthesis may impact the AYA TCS psychosexual development, this would suggest that medical teams discussing this treatment option can consider discussing the potential benefits related to self-image and reassurance, especially considering the high levels of satisfaction with the prosthesis reported by TCS (Dieckmann et al., 2015). This is particularly important as some clinicians' perspectives on prosthesis seemed key in the participants accepting it or not, and equally important to remember that trust in the clinicians appears particularly high during this vulnerable period of the AYA TCS (and close others) life.

Implications For Future Research

The present research provides an initial step towards understanding the psychosexual identity development in AYA TCS. Future research could seek to establish clinicians' perceptions of the various aspects of AYA TC diagnosis and treatment. For example, do they feel prosthesis is something that patients should accept? And does this influence their likelihood to offer it?

Future research may explore cultural differences in the development of psychosexual identity within this population. As previous research has shown masculine identity is heavily culture bound (e.g., Pleck et al., 1993), there may be key differences depending on cultural background.

Future research may also explore the adoption of stoicism in other cancer survivors, such as teenage cervical cancer survivors to explore gender differences. This would explore whether attributes associated with masculinity (e.g., stoicism) may equally apply to non-males. Research may also explore clinicians' attitudes towards these traits – perhaps medical staff prefer more stoic patients as it eases the psychological burden of their already highly emotive work?

Conclusion

This study demonstrated the influence of TC on psychosexual identity development in AYA TCS. The findings were consistent with previous literature, illustrating that masculine development may be contributed to by close relations and may be irrespective of physical changes to the body. The initial shock of diagnosis may contribute to adoption of harmful 'traditional' masculine traits, such as stoicism, which also seem to serve a purpose of managing the initial distress. The initial distress may prove to be unresolved, as potentially evidenced by the avoidance of saying words such as 'testicle', 'sperm' or 'cancer'. The weight of responsibility can be difficult for AYA patients to manage, thus they defer responsibility surrounding treatment and prosthesis to clinicians and close others. These close others also seem to be who the AYA TCS actively reassures throughout their experience. The experience does seem to strengthen the close relationship, but also create anxiety surrounding future romantic partners – particularly in those who did not receive a prosthesis. Nonetheless, TC even provided inspiration to some AYA to pursue medical careers or shifted their personalities away from 'traditional' masculine traits of violence and aggression. This study suggests that psychological input may help facilitate AYA TCS away from 'traditional' masculine traits and thus aid in their psychosexual identity development.

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Section C: Appendixes and Supporting Material

Appendix A critical appraisal skills programme (CASP) criteria for qualitative research studies.

Section A: Are the results valid?

1. Was there a clear statement of the aims of the research?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aims of the research?
4. Was the recruitment strategy appropriate to the aims of the research?
5. Was the data collected in a way that addressed the research issue?
6. Has the relationship between researcher and participants been adequately considered?

Section B: What are the results?

7. Have ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of findings?

Section C: Will the results help locally?

10. How valuable is the research?

Appendix B: Information sheet for participants.

Salomons
Institute for Applied
Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG
www.canterbury.ac.uk/appliedpsychology

Information about the research

Impact On Development Following Recovery From Testicular Cancer During Adolescence

Hello. My name is Abdullah Aldiwan and I am a trainee clinical psychologist at Canterbury Christ Church University. I would like to invite you to take part in a research study. Before you decide whether to take part, it is important that you understand why the research is being done and what it would involve for you.

Please do talk to others about the study if you wish and discuss your participation.

(Part 1 tells you the purpose of this study and what will happen to you if you take part.
Part 2 gives you more detailed information about the conduct of the study).

What is the purpose of the study?
The research will hopefully provide a greater understanding of the experiences of survivors of testicular cancer, where the diagnosis and treatment was between the ages of 14 – 19. The aim is to understand how it was experienced and what meanings people give to different facets of the experience. This includes the support received, the social and personal effects of the diagnosis and treatment and any impact it had on your sense of identity. Ideally, it is hoped that this research will help develop policies to assist all professionals working in this field to work more effectively together to improve the experience and minimise consequences.

Why have I been invited?
I would invite you to talk about what it was like to receive the diagnose and to undergo treatment of testicular cancer in your teenage years. You may have been contacted by the team at UCLH before giving consent for me to contact you. We aim to interview around 10 others in similar positions. I would like to know about the process of receiving the diagnosis and treatment, how this impacted you and your relationships, the support you received and any lasting impacts.

Do I have to take part?
It is up to you to decide whether to join the study. If you agree to take part, I will then ask you to sign a consent form. You are free to withdraw at any time during the interview, without giving a reason.

What will happen to me if I take part?
If you would like to take part in the study, you will be asked to read and sign the consent form attached and return it to the address (physically by post or scanned and emailed).

Following receipt of consent, I will contact you to arrange a date and time for us to meet virtually. Due to the global pandemic this will be carried out virtually through video conferencing software. The calls can occur between 8am and 9pm (with the latest possible time of starting at 7pm).

You will be provided the opportunity to discuss any questions you have about the research process. We will then talk together in an interview which should last roughly an hour. The interview will be partly structured in that there are some topics that I hope will be covered, but we will also have the opportunity to explore and discuss your experiences and any issues that are pertinent. You may take a 15-minute break at any point of the interview.

We will also collect some demographic data from you, such as current age, ethnicity, diagnosis during adolescence, date of diagnosis, treatment length, time since finished treatment, and region of UK treatment occurred. This is to help with our analysis and improve the quality of our results.

What are the possible disadvantages and risks of taking part?

We understand that this will be a sensitive area to focus on. Therefore it may be challenging to talk about and may evoke some distress in you. Our intention is not to cause upset or anger, but to explore the emotion and meanings underpinning your experiences.

What are the possible benefits of taking part?

You will be helping to provide valuable, rich information on how to better support people diagnosed in future. This can help professionals manage their physical, emotional and psychological well-being better. We cannot promise the study will help you but the information we get from this study will help improve the treatment of people with testicular cancer in future.

Expenses and payments

There will be no monetary compensation for taking part in this research.

What if there is a problem?

Any complaint about the way you have been dealt with during the study or any possible harm you might suffer will be addressed. The detailed information on this is given in Part 2.

Will information from or about me from taking part in the study be kept confidential?

Yes. We will follow ethical and legal practice and all information about you will be handled in confidence. There are some rare situations in which information would have to be shared with others. The details are included in Part 2.

This completes part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

Part 2 of the information sheet

What will happen if I don’t want to carry on with the study?

If you wish to withdraw from the study at any point of the interview, you are entitled to do so. We will ask if you wish for us to withdraw and destroy the data gathered during our interview. If this is your wish, then the data will be destroyed and not included in the research. If you do not wish for us to destroy the data, it will be used in the final report as it may still hold valuable information pertinent to the research aims.

If you wish to withdraw after the interview has been completed, it may still be possible to extract and destroy your data, provided this is completed within two weeks of our interview date (14 days). After this point it will no longer be possible to extract and destroy the data as it will have been analysed and mixed with the data collected from other participants. The data will always remain anonymous.

What if there is a problem?

We take all and every complain seriously and will be reviewed by the lead investigator if necessary at Canterbury Christ Church University.

What if I become distressed during the interview?

I will not try to distress you and will make every attempt to ensure the interview is not upsetting. However, I understand that the topic may be emotionally challenging and this may happen. We may pause the interview for 15 minutes if you feel unable to continue at this stage, or end the interview altogether if this is necessary.

At the start of the interview, I will remind you that everything we discuss will remain confidential, unless I am concerned of any risk of harm posed to yourself, others or from others. If this is the case, I may have to stop the interview and break confidentiality. You will be immediately informed if this was to occur.

If there is no immediate risk, but you are significantly distressed and request further support to help manage this, I will signpost you to appropriate services that may be able to help. I will also offer a follow up call at a later date to answer any more questions or concerns.

How will you use the information about me?

We (Canterbury Christ Church University, as sponsor) will need to use information from you for this research project.

This information will include your current age, ethnicity, diagnosis during adolescence, date of diagnosis, treatment length, time since finished treatment and region of UK treatment occurred. People will use this information to do the research or to check your records to make sure that the research is being done properly.

We will keep all information about you safe and secure.

Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how my information is used?

- You can stop being part of the study at any time, without giving a reason.
- If you choose to stop taking part in the study, we would like to continue using information about you from the interview and data we gathered from you. If you do not want this to happen, tell us within 14 days of withdrawing from the study and we will stop.

- We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you, but we may ask you to verify it.

Where can I find out more about how my information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- by asking one of the research team
- by sending an email to AA771@canterbury.ac.uk, or
- by ringing us on XXXXXXXXXXX.

We will only contact you if you have previously consented to be contacted for research purposes. You details will be passed on to us through a secure NHS email.

We will not use any identifiable information in our research project, only information from our interview. This information will be kept safe, secure, and anonymised.

Once we have finished the study, we will keep some of the interview data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

Concerns and Complaints

If you have a concern about any aspect of this study, you should ask to speak to me and I will do my best to address your concerns. You can contact me by leaving a message on the 24-hour voicemail phone number xxxxxxxx. Please leave a contact number and say that the message is for Abdullah and I will get back to you as soon as possible. If you remain dissatisfied and wish to complain formally, you can do this by contacting Dr Fergal Jones, Clinical Psychology Programme Research Director, Salomons Institute for Applied Psychology –fergal.jones@canterbury.ac.uk

Will information from or about me be kept confidential?

We will take every measure to ensure that the data you provide during the research will be kept safe, secure and confidential. This will be done in a few ways:

- Any data you provide will stored on the secure audio recording device before being transcribed.
- After transcription, your recording will be immediately destroyed/deleted.
- The unedited data will only be accessible by myself and all information collected will be made anonymous – no identifiable information will be documented to ensure that you cannot be identified from the research.
- The lead researcher will be the only person who has access to any personally identifiable information.
- Should the lead researcher feel there is any risk of harm to you or others, then confidentiality may need to be broken.
- You have the right to check the accuracy of the data held about you and correct any errors.

Some of the (anonymous) data may be displayed as verbatim extracts in the final research to reinforce my analysis and interpretation, and the entire transcript will be submitted as part of the final project.

What will happen to the results of the research study?

It is understandable if you want to know results of a study you have been in.

- I will send you a summary of the findings.
- As mentioned in Part 1, the intention is to publish the research to an oncology journal in order to advance the knowledge base in this field. If it is published, I can also send out the article if you would like a copy.
- This includes providing better insight and understanding of the difficulties people with a diagnosis of testicular cancer between the ages of 14 – 19 experience.
- With better insight, we can hopefully improve the quality of care provided.

Who is sponsoring and funding the research?

This study was organised by the lead researcher Abdullah Aldiwan with input from a lead Supervisor Dr James McParland and Internal supervisor Dr Tamara Leeuwerik, as part of the lead researcher's Clinical Psychology doctoral training at Canterbury Christ Church University.
The university has funded this study.

Who has reviewed the study?

All research in the NHS is looked at by an independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by the NHS Research Ethics Committee on 14/04/2021 and given favourable opinion by The Salomons Ethics Panel and the UCLH ethics committee.

Should you wish to take part, you will be given a copy of this information sheet to keep for your records in addition to a copy of your signed consent form

Requesting study results

If you would like a summary of the research findings following its completion, please email me at: AA771@canterbury.ac.uk and I will be happy to send you a copy.

Further information and contact details

Should you require further information regarding this research project, please do not hesitate to contact me via email at: AA771@canterbury.ac.uk.
Alternatively, you can leave a message for me on a 24-hour voicemail phone line at 07927596524. Please say that the message is for Abdullah Aldiwan and leave a contact number so that I can get back to you.

If you would like to speak to the member of the research department who is supervising the study and is very experienced in this field of research, please contact Tamara Leeuwerik at tamara.leeuwerik@canterbury.ac.uk.

Appendix C: Consent form

Salomons Institute for Applied Psychology
One Meadow Road, Tunbridge Wells, Kent TN1 2YG

CONSENT FORM

Title of Project:
Development of psychosexual identity following recovery from testicular cancer during adolescence

Name of Researcher: *Abdullah Aldiwan*

Please initial box

1. I confirm that I have read and understand the information sheet dated 16/04/2021 (version 3) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily. ☐

2. I agree to engage in a video-conferencing software based interview lasting roughly 1 hour with the potential for a 15 minute break. This may occur Monday to Saturday from 8am with the last interview time at 7pm. ☐

3. I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason. ☐

4. I understand that relevant sections of my data collected during the study may be looked at by the lead supervisor James McParland. I give permission for these individuals to have access to my data. ☐

5. I understand that I am giving permission for my anonymous data to be displayed as verbatim extracts in the researcher's write-up, and that the anonymised transcripts may need to be submitted as part of the researcher's thesis. ☐

6. I agree for my anonymous data to be used in further research studies ☐

7. I agree to take part in the above study. ☐

Name of Participant______________________ Date_________________

Signature _____________________

Name of Person taking consent _______________ Date______________

Signature ______________________

Appendix D: Interview Schedule

1) Can you tell me about your experience of hearing about this research?
    a. What came to mind when you saw the advert?
    b. What prompted you to take part in this research?

2) Please describe your experience of being informed you had testicular cancer?
    a. What happened?
    b. What was your living situation at the time?
    c. Did you have a partner?
    d. Did you tell friends/partners about your diagnosis and/or treatment?
    e. How was having conversations around these intimate topics with professionals, friends and family?
    f. What options do you remember being offered?
    g. How did you feel?
    h. What did you think?
    i. How did you make sense of it?
    j. How did you manage your distress then?
    k. How do you manage distress now?

3) Can you tell me how being informed about the testicular cancer affected your relationships with other people if at all,?
    a. What about family?
    b. What about friends?
    c. What about sexual partners?

<u>Would it be ok to ask about how you felt about your sexual experiences?</u>

- (If no, is there anything that may make it more comfortable to talk about? May need to reassure them about confidentiality and that they don't have to talk about it if they do not want to).

-Normalise through conveying that testicular cancer in adolescence has impact on sexual experience according to research. Making it clear why I am asking.

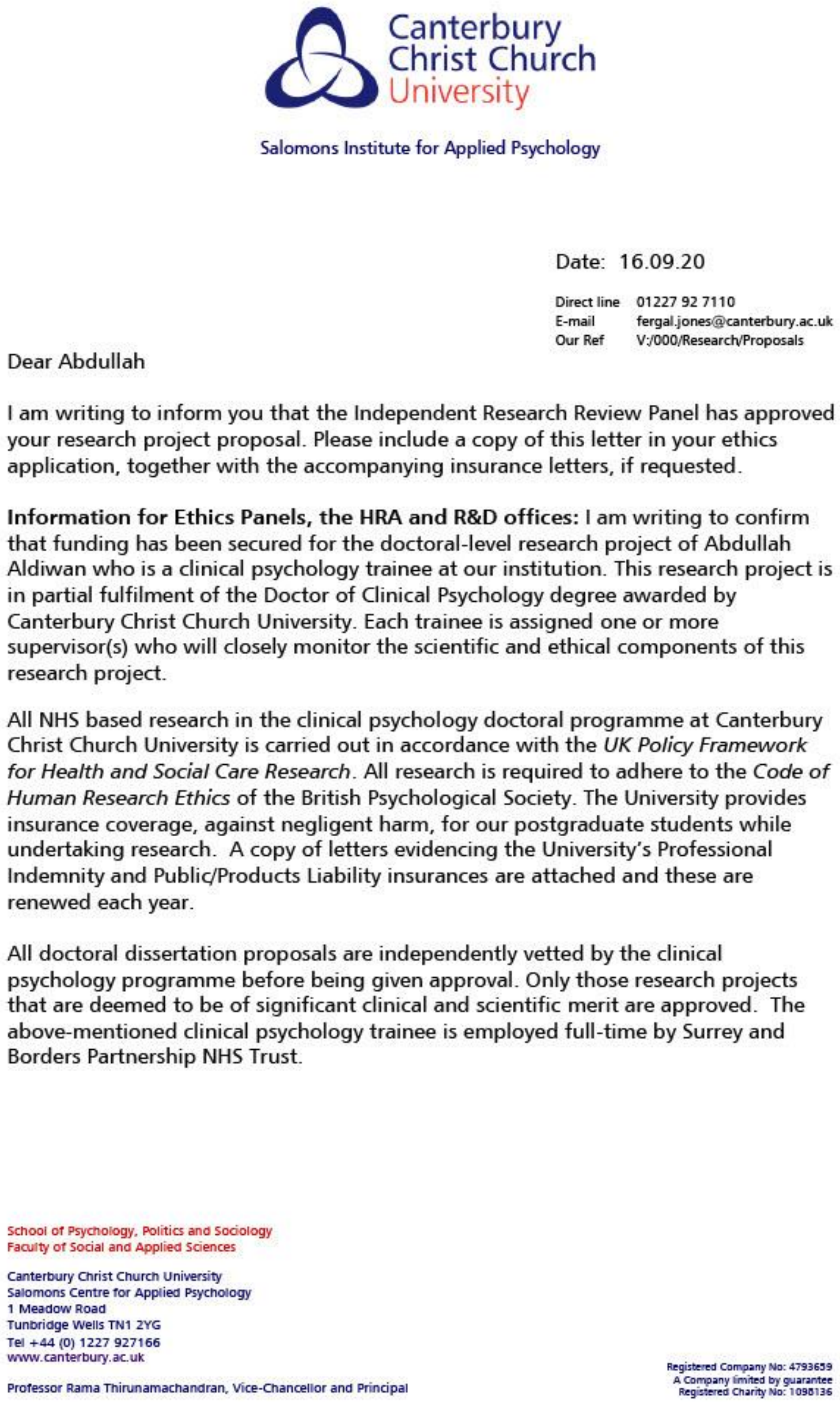
4) How do you perceive the impact on your sexual experience following diagnosis and treatment?
    a. What, if any, were your concerns?
    b. How (if at all) did your self-perception change throughout treatment?
        i. What (if anything) contributed to this change?
        ii. How did you feel before?
        iii. How did you feel after?
    c. How was your first sexual experience?
    d. Were there any changes to your sex drive?

5) What support were you offered at the time and since?
    a. What was your experience of the psychological support being offered?
    b. What was your experience of the medical support being offered?
    c. How did you feel about the support you were offered?
    d. What might have helped at that time?
    e. What influenced your choice around prosthetics?
    f. What has made you want to engage or disengage with services?

6) Whether and how has testicular cancer changed how you feel about yourself?
    a. How has it affected how you think or feel about yourself?

7) What else do you feel would be important to know?

Appendix E: University Ethics Approval



Canterbury
Christ Church
University

Salomons Institute for Applied Psychology

Date: 16.09.20

Direct line 01227 92 7110
E-mail fergal.jones@canterbury.ac.uk
Our Ref V:/000/Research/Proposals

Dear Abdullah

I am writing to inform you that the Independent Research Review Panel has approved your research project proposal. Please include a copy of this letter in your ethics application, together with the accompanying insurance letters, if requested.

Information for Ethics Panels, the HRA and R&D offices: I am writing to confirm that funding has been secured for the doctoral-level research project of Abdullah Aldiwan who is a clinical psychology trainee at our institution. This research project is in partial fulfilment of the Doctor of Clinical Psychology degree awarded by Canterbury Christ Church University. Each trainee is assigned one or more supervisor(s) who will closely monitor the scientific and ethical components of this research project.

All NHS based research in the clinical psychology doctoral programme at Canterbury Christ Church University is carried out in accordance with the *UK Policy Framework for Health and Social Care Research*. All research is required to adhere to the *Code of Human Research Ethics* of the British Psychological Society. The University provides insurance coverage, against negligent harm, for our postgraduate students while undertaking research. A copy of letters evidencing the University's Professional Indemnity and Public/Products Liability insurances are attached and these are renewed each year.

All doctoral dissertation proposals are independently vetted by the clinical psychology programme before being given approval. Only those research projects that are deemed to be of significant clinical and scientific merit are approved. The above-mentioned clinical psychology trainee is employed full-time by Surrey and Borders Partnership NHS Trust.

School of Psychology, Politics and Sociology
Faculty of Social and Applied Sciences

Canterbury Christ Church University
Salomons Centre for Applied Psychology
1 Meadow Road
Tunbridge Wells TN1 2YG
Tel +44 (0) 1227 927166
www.canterbury.ac.uk

Professor Rama Thirunamachandran, Vice-Chancellor and Principal

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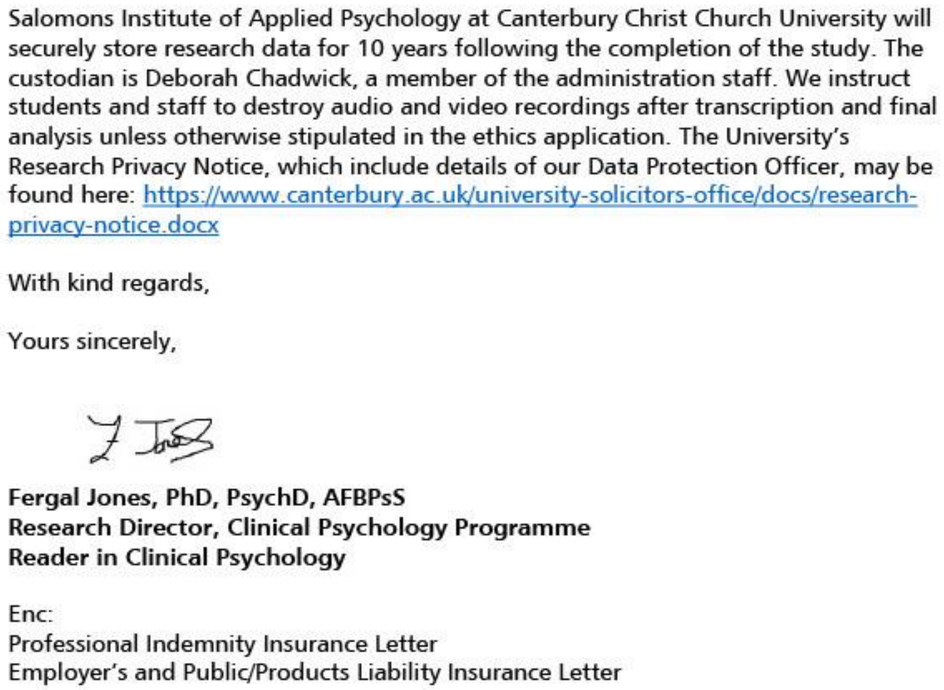
Registered Charity No: 1098136



Salomons Institute of Applied Psychology at Canterbury Christ Church University will securely store research data for 10 years following the completion of the study. The custodian is Deborah Chadwick, a member of the administration staff. We instruct students and staff to destroy audio and video recordings after transcription and final analysis unless otherwise stipulated in the ethics application. The University's Research Privacy Notice, which include details of our Data Protection Officer, may be found here: https://www.canterbury.ac.uk/university-solicitors-office/docs/research-privacy-notice.docx

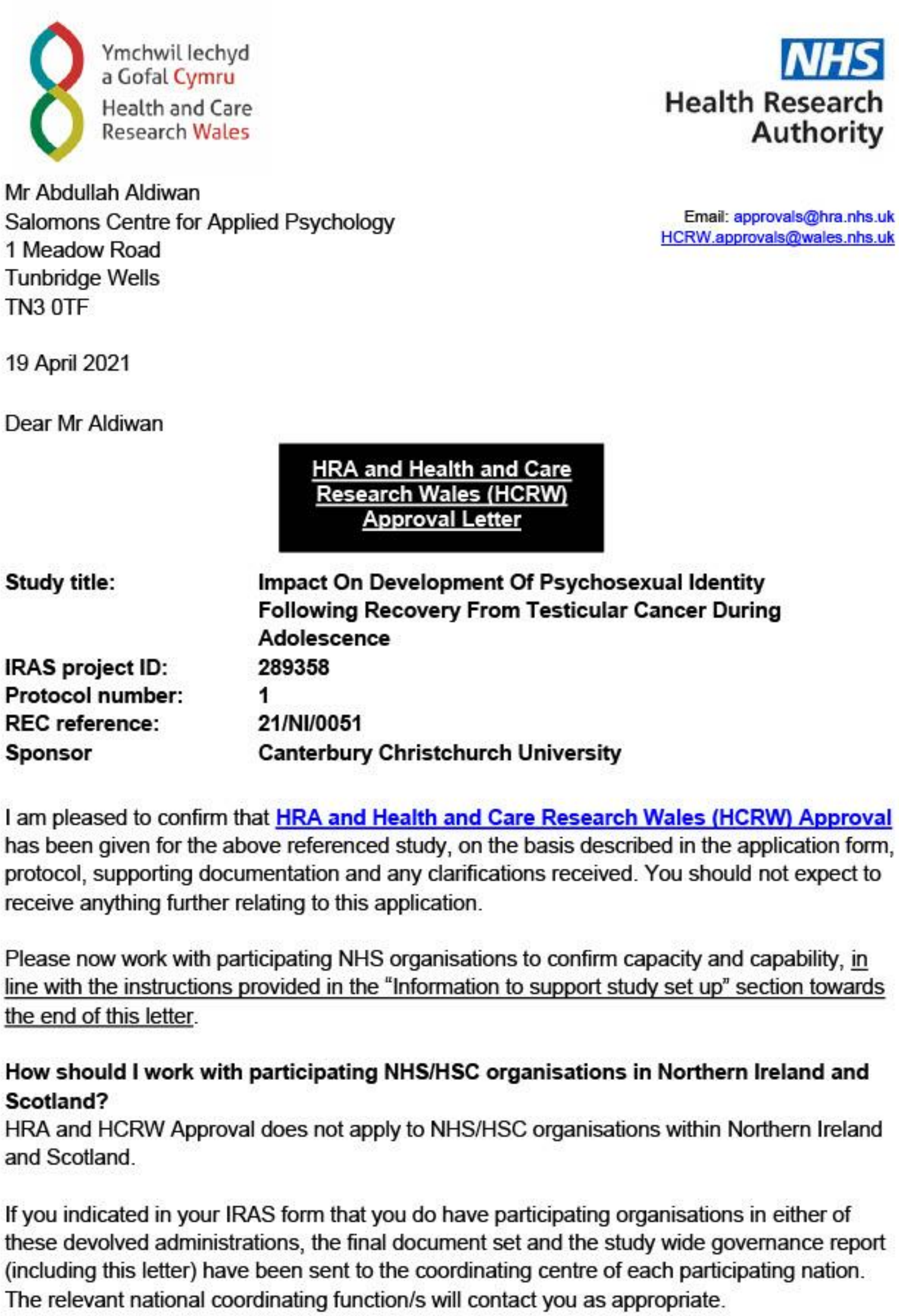
With kind regards,

Yours sincerely,

Fergal Jones, PhD, PsychD, AFBPsS
Research Director, Clinical Psychology Programme
Reader in Clinical Psychology

Enc:
Professional Indemnity Insurance Letter
Employer's and Public/Products Liability Insurance Letter

Appendix F: NHS Ethics Approval



Ymchwil Iechyd
a Gofal Cymru
Health and Care
Research Wales

NHS
Health Research
Authority

Mr Abdullah Aldiwan
Salomons Centre for Applied Psychology
1 Meadow Road
Tunbridge Wells
TN3 0TF

Email: approvals@hra.nhs.uk
HCRW.approvals@wales.nhs.uk

19 April 2021

Dear Mr Aldiwan

HRA and Health and Care Research Wales (HCRW) Approval Letter

Study title: **Impact On Development Of Psychosexual Identity Following Recovery From Testicular Cancer During Adolescence**
IRAS project ID: **289358**
Protocol number: **1**
REC reference: **21/NI/0051**
Sponsor **Canterbury Christchurch University**

I am pleased to confirm that HRA and Health and Care Research Wales (HCRW) Approval has been given for the above referenced study, on the basis described in the application form, protocol, supporting documentation and any clarifications received. You should not expect to receive anything further relating to this application.

Please now work with participating NHS organisations to confirm capacity and capability, in line with the instructions provided in the "Information to support study set up" section towards the end of this letter.

How should I work with participating NHS/HSC organisations in Northern Ireland and Scotland?

HRA and HCRW Approval does not apply to NHS/HSC organisations within Northern Ireland and Scotland.

If you indicated in your IRAS form that you do have participating organisations in either of these devolved administrations, the final document set and the study wide governance report (including this letter) have been sent to the coordinating centre of each participating nation. The relevant national coordinating function/s will contact you as appropriate.

Please see IRAS Help for information on working with NHS/HSC organisations in Northern Ireland and Scotland.

How should I work with participating non-NHS organisations?
HRA and HCRW Approval does not apply to non-NHS organisations. You should work with your non-NHS organisations to obtain local agreement in accordance with their procedures.

What are my notification responsibilities during the study?

The standard conditions document "*After Ethical Review – guidance for sponsors and investigators*", issued with your REC favourable opinion, gives detailed guidance on reporting expectations for studies, including:

- Registration of research
- Notifying amendments
- Notifying the end of the study

The HRA website also provides guidance on these topics, and is updated in the light of changes in reporting expectations or procedures.

Who should I contact for further information?
Please do not hesitate to contact me for assistance with this application. My contact details are below.

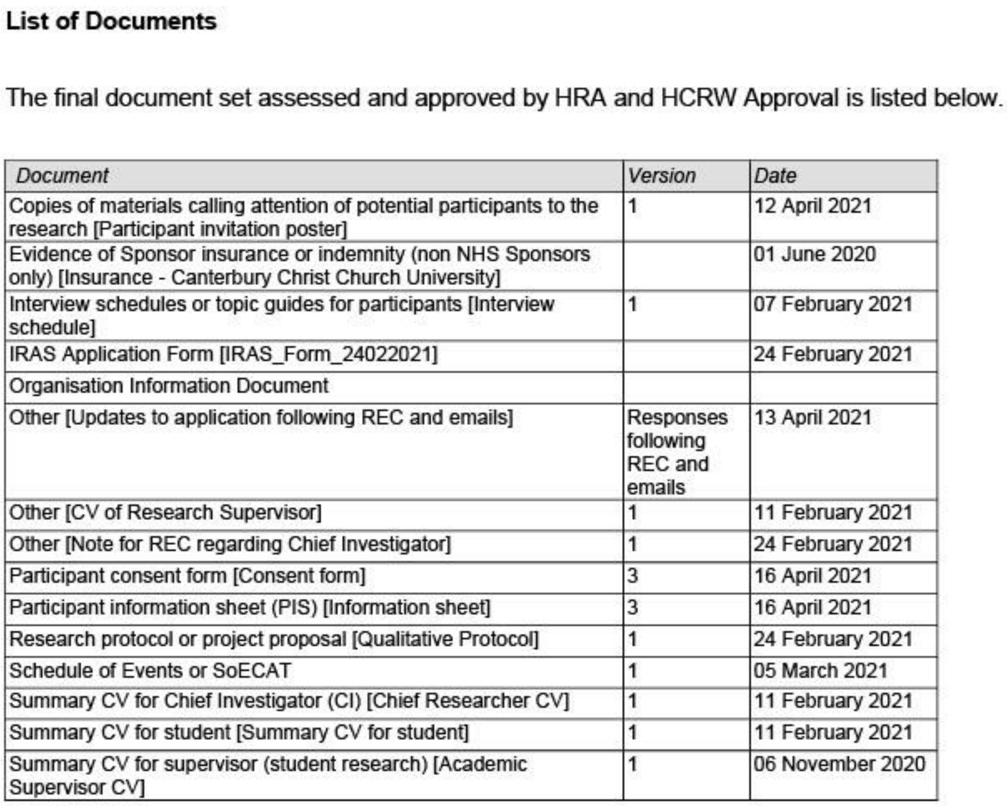
Your IRAS project ID is **289358**. Please quote this on all correspondence.

Yours sincerely,

Michael Pate
Approvals specialist

Email: approvals@hra.nhs.uk

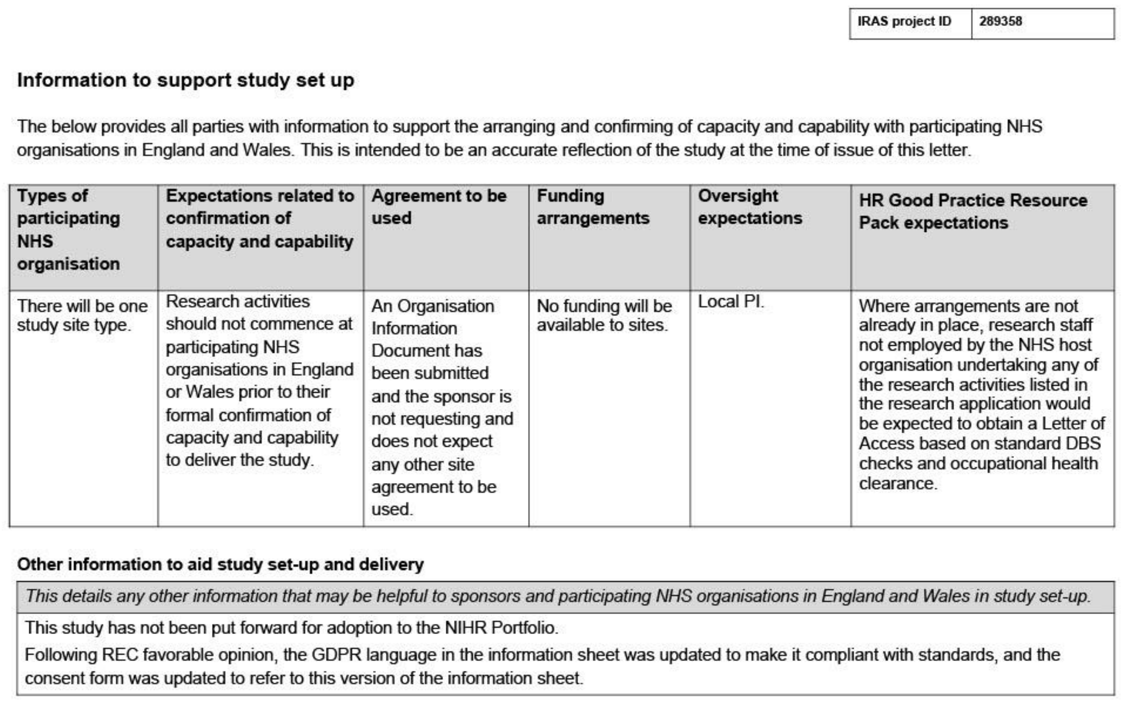
Copy to: *Ms Hannah Tubb*



List of Documents

The final document set assessed and approved by HRA and HCRW Approval is listed below.

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Participant invitation poster]	1	12 April 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance - Canterbury Christ Church University]		01 June 2020
Interview schedules or topic guides for participants [Interview schedule]	1	07 February 2021
IRAS Application Form [IRAS_Form_24022021]		24 February 2021
Organisation Information Document		
Other [Updates to application following REC and emails]	Responses following REC and emails	13 April 2021
Other [CV of Research Supervisor]	1	11 February 2021
Other [Note for REC regarding Chief Investigator]	1	24 February 2021
Participant consent form [Consent form]	3	16 April 2021
Participant information sheet (PIS) [Information sheet]	3	16 April 2021
Research protocol or project proposal [Qualitative Protocol]	1	24 February 2021
Schedule of Events or SoECAT	1	05 March 2021
Summary CV for Chief Investigator (CI) [Chief Researcher CV]	1	11 February 2021
Summary CV for student [Summary CV for student]	1	11 February 2021
Summary CV for supervisor (student research) [Academic Supervisor CV]	1	06 November 2020



IRAS project ID	289358

Information to support study set up

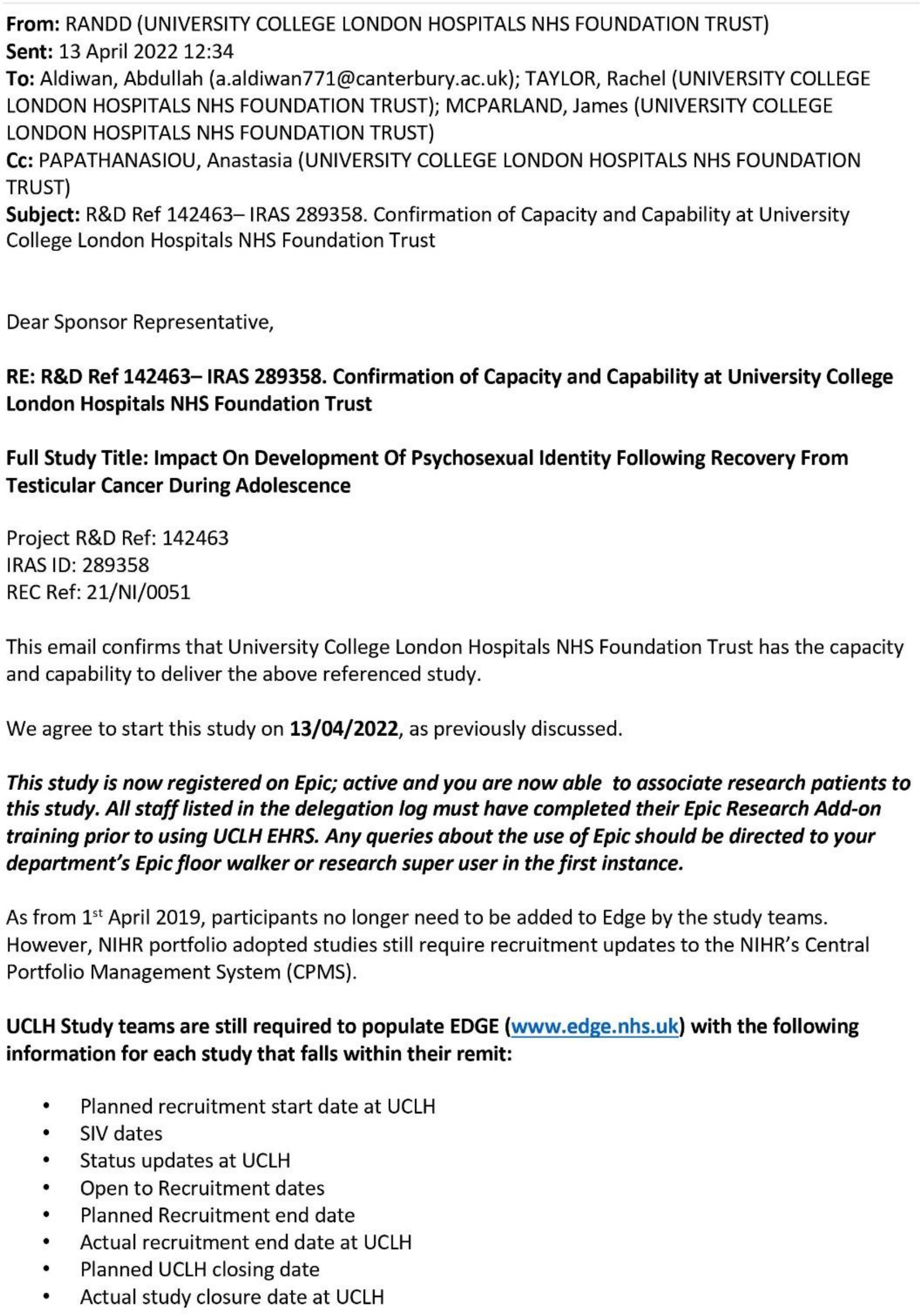
The below provides all parties with information to support the arranging and confirming of capacity and capability with participating NHS organisations in England and Wales. This is intended to be an accurate reflection of the study at the time of issue of this letter.

Types of participating NHS organisation	Expectations related to confirmation of capacity and capability	Agreement to be used	Funding arrangements	Oversight expectations	HR Good Practice Resource Pack expectations
There will be one study site type.	Research activities should not commence at participating NHS organisations in England or Wales prior to their formal confirmation of capacity and capability to deliver the study.	An Organisation Information Document has been submitted and the sponsor is not requesting and does not expect any other site agreement to be used.	No funding will be available to sites.	Local PI.	Where arrangements are not already in place, research staff not employed by the NHS host organisation undertaking any of the research activities listed in the research application would be expected to obtain a Letter of Access based on standard DBS checks and occupational health clearance.

Other information to aid study set-up and delivery

This details any other information that may be helpful to sponsors and participating NHS organisations in England and Wales in study set-up.
This study has not been put forward for adoption to the NIHR Portfolio. Following REC favorable opinion, the GDPR language in the information sheet was updated to make it compliant with standards, and the consent form was updated to refer to this version of the information sheet.

Appendix G: UCLH Research and Development Approval



From: RANDD (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST)
Sent: 13 April 2022 12:34
To: Aldiwan, Abdullah (a.aldiwan771@canterbury.ac.uk); TAYLOR, Rachel (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST); MCPARLAND, James (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST)
Cc: PAPATHANASIOU, Anastasia (UNIVERSITY COLLEGE LONDON HOSPITALS NHS FOUNDATION TRUST)
Subject: R&D Ref 142463– IRAS 289358. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust

Dear Sponsor Representative,

RE: R&D Ref 142463– IRAS 289358. Confirmation of Capacity and Capability at University College London Hospitals NHS Foundation Trust

Full Study Title: Impact On Development Of Psychosexual Identity Following Recovery From Testicular Cancer During Adolescence

Project R&D Ref: 142463
IRAS ID: 289358
REC Ref: 21/NI/0051

This email confirms that University College London Hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study.

We agree to start this study on **13/04/2022**, as previously discussed.

This study is now registered on Epic; active and you are now able to associate research patients to this study. All staff listed in the delegation log must have completed their Epic Research Add-on training prior to using UCLH EHRS. Any queries about the use of Epic should be directed to your department's Epic floor walker or research super user in the first instance.

As from 1st April 2019, participants no longer need to be added to Edge by the study teams. However, NIHR portfolio adopted studies still require recruitment updates to the NIHR's Central Portfolio Management System (CPMS).

UCLH Study teams are still required to populate EDGE (www.edge.nhs.uk) with the following information for each study that falls within their remit:

- Planned recruitment start date at UCLH
- SIV dates
- Status updates at UCLH
- Open to Recruitment dates
- Planned Recruitment end date
- Actual recruitment end date at UCLH
- Planned UCLH closing date
- Actual study closure date at UCLH

I attach a user guide which provides information around how to complete the above. If anything is unclear, a member of the JRO Research Data and Information team will be happy to help. Please make contact via UCLH.RandD@nhs.net

Kind Regards

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Appendix H: Example section of David's Coded transcript with exploratory notes and experiential statements.

Experiential Statements	Transcript	Exploratory notes
	R OK so can you tell me about your experience of hearing about this research	
Desire to help others through experience	**P** Do you mean you calling me? because I just remember a few years ago the consultant mentioned if I was happy to be called about any research and I said yeah I'm happy for anything. Then when you called me I was, well, I just thought anyway that it can be improved for other people or made better or bit more understanding about it for other people that it's always a win.	Desire to help others in similar situation. Desire to raise awareness.
	R OK so that's what came to mind when I gave you a call was there anything else that came to mind	
Delaying processing until later	**P** Obviously other than the standard of some random number calling me (laugh) but then obviously because you mentioned Dr Stoneham (silence) made it clear you weren't just some randomer. Was there anything else? (Silence 5 seconds) I guess it just made me think about it all because after seven years you just don't think about it (silence 10 second) other than that no.	No longer thinking about it - Sense of having moved on?
	R Could you tell me about what prompted you to take part in the research which you briefly touched on.	
	P Okay so it was mainly, well I always liked helping out with anything to do with these kinds of things, like I said anything more I can try to help research	Resentment towards

Desire to help others through experience	into, because obviously this research into treatments but your focus seems to more of the experience of the whole things considering the niche and it's not really looked into at all and I remember when I was diagnosed right towards the end of my school time literally a few weeks before my first exam hey level exam, I think it was the year before we had someone come in to talk to the sick for about how to diagnose it. she must have been a 50 or 60 year old lady an she spoke about her son and that his son went on to die from it but she basically brought in a pair of silicone balls and use that to tell people how to check themselves and it's not the right message you're trying to convey that if you going to get diagnosed testicular cancer you're going to die (laughs) and it's not really the right kind of person to explain it. since then I have been back into the school twice to talk about my experience and to try, get rid of the stigma behind it I tried to make it a bit funny because nowadays council doesn't equal death anymore for some yes, however I think this is quite an important thing to try -because even when I have patients on the ward now I say we're trying to investigate them for cancer not necessarily in those words but people suddenly shutdown and I think there does need to be research into how or what peoples experience of it isn't how to improve that experience. that was a long-winded answer. **R** Not at all but that does move us onto our next question which is could you please tell me about your experience of being	pre-existing experience of TC and checking. Understanding of the research aims. Alluding to men sharing experience? 'It' described, not testicular cancer. Desire to eliminate stigma and make it less awkward to others. Desire to improve others experience of it. Awareness that speakers approach and gender were important in conveying the 'right' type of message? Desire to improve others experience of it.

	diagnosed with testicular cancer.	
Being ‘psychologically strong – emotions seen as bad Delaying processing until later	**P** Erm (silence 10 seconds) I was actually told in the car park whilst walking from the radiology department. is the car park round the back with the ambulance park and I was walking with the nurse from radiology we somehow walked out sides back in through the entrance I don't really know where I was walking to maybe to the consultants office and I don't know whether she knew I wanted to be told or whether she knew I hadn't already been told or whatever but actually for me that was quite a good way of being told it was very matter of fact it was, also that speaks to my personality as I just get on with things, I just do it. So to me and for me everyone's different there's no point breaking down and being all emotional about it this is the situation you move on you look about the solution is, so for me that was fine and I didn't really think much of it maybe because I was also having my exams at the same time I just pushed through. I think it hit me more if he wants later when I was thinking ‘oh I went through that hmm.’ But at the time it was more just you know you've been diagnosed with this health condition, cool.	Accidental disclosure from nursing staff, but taken well by David. Naturalistic setting alleviated shock. Emotions seen as getting in the way? Sense of keeping calm after diagnosis. Maintaining a pragmatic approach. No sense of emotional response from diagnosis.
	R It sounds like the way it happened was very fitting for you, what do you think?	
	P Yes absolutely.	
	R And what was your living situation at the time?	
	P I was living with my parents and	Presence of close family.

	going to school and I lived with my brother.	
	R Did you have a partner at the time?	
	P No	
Desire to help others through experience	**R** Did you tell your friends and family or partners about the diagnosis and treatment.	
	P Actually something else I was going to say about one of the other questions I was asked about how I was told, at medical school we are taught to when you're breaking bad news, are you a medical doctor?	Memories returning through prompting?
	R Clinical psychology	
Being 'psychologically strong – emotions seen as bad Solution focussed approach	**P** Clinical Psychology OK so we're told to give the bleep to someone else go to a side room make everything quiet tell them and allow them to respond and I think for me that would have been an awful way to do it. I don't think that's right, and I think that whilst maybe for the majority of the population I really don't know but sometimes I think that can hinder the whole process but.	Idea of individualising manner in which you tell someone. Inviting emotion would have been a hindrance.
	R Tell me more about that	
Complications arising from close others	**P** (Silence 10 seconds) I think for me it would have made me think too much about the emotional side of things and that meant I wouldn't have thought straight about the treatments and the solutions, whatever about the treatment possibilities. I think that maybe it would have, erm, (silence 10) it's almost like people would have been expecting something off me to respond in a certain way that isn't	Switching off emotions helped when being diagnosed, helped with being pragmatic? Desire to be pragmatic and not have emotional reaction 'invited' by others. Emotional expression

Reassurance from close others	me. for me it was fine to be told this is it this is the situation these are the possibilities this is the treatment plan because in the way that we taught you tell someone that diagnosis and you love him to respond rather than you tell them the diagnosis and the treatment possibilities ie you saying it's not death sentence and then allow them to respond after that. Making the whole situation or taking them to the side room and having someone else who can scribe and this that and the other it makes it a bit heavy the whole situation quite pressurised I think.	alluding to ‘not being me’. Concern over inviting emotions in others diagnosed in similar situation seen as bad.
	R And it seems like you're insinuating that it adds to the emotional situation in the room and it changes the emotional side of you the recipient of the news. With the disclosure in mind did you tell your friends and family or partner by their diagnosis and treatment side of it?	
Being ‘psychologically strong – emotions seen as bad Delaying processing until later	**P** My dad is a doctor and when I felt a lump in the first place I went to him straight away and was like what do I do? So my parents were very much part of the whole journey. (silence 8 seconds). And therefore my brother because we're quite an open family. (silence 10 seconds). My friends even to this day I've kept it quite, it's something people don't necessarily need to know about me. I've told some friends as in I've told my very close friends so maybe that's 10/15 people, I've told my girlfriend now but other than that it's not something that I feel like I need to stand on a pedestal and announce to the world I think it's just something	Immediate family have knowledge to help and support. No sense of obligation to tell people. Idea that it can be concealed from others. Telling others equated to announcing it on a pedestal (to a degree).

	about me and I've only really told people if I think it's something they not need to know but Can know.	
	R What was it like telling them all?	
How medical teams helped Concerns for the future regarding self	**P** Erm (silence 9 seconds) it almost became harder over time and has become easier since. At the time I remember telling friends from school, I think I told three or four friends from school what I was going through it I remember the girls I told just burst out crying, and the I told one guy and he was just very matter of fact about it I think didn't quite know how to handle it but (silence 5 seconds) I was very matter of fact about it, since telling people I have found it quite hard to say the word cancer I don't know why it's almost like I say 'I had' and then there's a long pause and because I physically can't say the word. I don't know why I'm fine now perfectly fine. (Silence 10 seconds) and then maybe in the past three years it's become a bit easier I still have that pause but (silence 5 seconds) it's become easier but it's still like don't tell people like my flatmate now I haven't told him because he doesn't need to know. I like to keep it quiet, I like to control who knows.	Emotional detachment helped disclosure? Struggles to say the word cancer. Unprocessed? Evokes anxiety? Unconscious sense of thought/action fusion? Unsure of mechanism around being unable to say the word. Perhaps flatmate is not a close friend? Therefore no disclosure?
	R There's almost an intimacy with who needs to know.	
	P That's yes that's also to do with the area that it's in.	
Delaying processing until later	**R** Surrounding the intimacy, how was having the conversations about the intimate areas with other people? Including professionals family and friends	

		if they happened.	
How medical teams helped	**P**	(silence 5 seconds) With medical professionals it was fine (Silence 5 seconds) I don't know whether this is because you know I had my medical school interviews I was a bit more thinking that way, not like what I am now obviously but because they were a bit more factual about it and it didn't they didn't shy away from talking about testicles or whatever. When I've been telling my friends I haven't been going into the specifics of treatment, having a prosthesis now in place I haven't really told, I think I told one really close friend and my girlfriend but that's it and my family obviously my family know everything from start to finish. But my friends I haven't really told and we don't really talk about how it was treated or whatever they just know that I had surgery and they had chemo but that's it.	Professionals feeling confident in the discussion made it easier? Able to mention testicle when discussing clinicians, sign of personal detachment? Non-disclosure of prosthetic to close friends – shame? Embarrassment?
	R	OK what about with the professionals?	
Delaying processing until later Being ‘psychologically strong – emotions seen as bad	**P**	That's actually a point I haven't thought about the sperm banking side the things as the treatment. I didn't tell my friends at all I haven't told anyone other than my family. (Silence 5 seconds) Why that is I don't know I just think it's sort of a weird thing to talk about I guess. My family know during the whole thing they took me to the appointments and everything we don't really talk about it since then because it's just something that's happened is there there's not really anything to talk about.	Did not consider certain treatments as ‘treatment’ at the time, even as ps an MD. Non-disclosure of spermbanking to others – shame? Embarrassing? Unnecessary detail?
	R	It sounds like your parents were	

	present for the conversations you had to the professionals. What was that like?	
How medical teams helped	**P** It was fine actually because of the way the professionals spoke about it they just said, they kept it very matter a fact about what the point of it was. Obviously I appreciate it but they didn't go into the intimacy of how it's all done, because that would have probably just been unnecessary especially in front of my parents, but the reasoning why I thought it was fine maybe. It was a little bit embarrassing I don't really remember because it was such a long time ago but it was literally embarrassing because of the nature of the topic but I think that they were very professional, very, very good. Yep.	Context sensitive clinicians helped with intimate topics when parents were around. Suppressing memory? Slight embarrassment with intimate convo, offset by professionalism of staff.
	R And what options do you remember being offered for treatment?	
Solution focussed approach	**P** I remember being offered I think it was, again this is ages ago, (silence 15 seconds) I think I was offered a few different options, the one being the one I had which is orchidectomy plus (silence 5 seconds) one dose of chemotherapy and then I think there was another treatment option which was a partial orchidectomy plus more cycles of chemotherapy and then I think there was another option which was just chemotherapy alone. (Silence 5 seconds) Plus sperm banking which again I didn't really think of that as a treatment option but obviously it is because going forward that's, chemotherapy impacts fertility so and chemotherapy as part of the treatment so you are right that's	Struggle to remember, result of emotional detachment? Intellectualising as an attempt to numb emotions?

	very, very true. (Silence 5 seconds) yeah those are the treatment options I was offered	
	R And how did you feel?	
Delaying processing until later Reassurance from close others Complications arising from close others	**P** I (silence 5 seconds) think it's always nice to be offered treatment options (silence 10 seconds) my parents were with me my dad was in there I can't remember what my mother was doing I think she was with my brother because he had exams as well but my dad was just like, it was very much 'we will go with whatever the consultant thinks is the best option for my health going forward'. And I felt that because she's very professional and she has a really good way of talking to the patients including me. I felt I can trust her, that she knew what she was talking about when she advised which treatment option was the best one, but it's still nice to be offered everything. oh obviously and the other treatment option of doing nothing which you always have to offer.	Full trust in consultants treatment decisions? Was father not involved? Did he also fully trust consultant? Consultants humanity helped David trust her judgment.
	R And there's something reassuring about the Dr Stonehams professionalism it sounds like. What did you think at the time?	
	P I just thought I want to get on with this and move on with my life.	Delayed making sense of it until it was over?
	R How did you make sense of it all?	
Complications arising from close others	**P** I don't think I did (silence 10 seconds), maybe I just thought this is just another thing in my life that I just have to another challenge of my life that I have to move past deal with and move	Emotional detachment? Pragmatic adoption?

	on.	
Concerns for the future regarding self	**R** And how did you manage any distress you may have had back then?	
	P I think being open with my family was quite good (silence 15 seconds) and I think actually it was quite good that I had my exams at the time because that was a really good distraction. (silence 5 seconds) yeah.	Family were supportive? Exams as a distraction from reality?
	R And how do you manage your distress now?	
	P I don't really have any to be honest.	Sense of no distress now.
	R Ok and you've mentioned some of your relationships can you tell me about how having testicular cancer affected your relationships if at all.	
	P I think the people that I told who are clearly concerned about me it may have brought us closer the people who I told who weren't openly caring it pushed us away and whether that was because they didn't know how to respond or because they generally didn't care about me because there are people who just don't care about you. yeah that pushed us away and I don't know why they reacted in the way that they did. so that was one example when I told someone who I thought I was close with and there was response with was that they laughed and I was really shocked by that I remember this was probably a year and a half after the treatment and diagnosis. and I think maybe sing spots that's maybe why I've continued to be quite private about it maybe I	Strengthened relationships with those actively caring, weakened with those whom did not react in this way. Uncertainty as to the reaction in others. Increased anxiety in disclosure? Friendships ending following their negatively perceived reaction to disclosure.

	don't know, I've literally just thought about that now.	
	R Sounds like that may have had an impact on you?	
	P Yes it may have done, I mainly don’t talk to that person now anymore also because our lives have moved away in different directions but I also wasn't really interested in speaking anymore to them or developing anymore that friendship.	Appreciation the negative reaction of others would have contributed to negative impact.
	R And what about sexual partners	
Sense of gaining from experience	**P** Erm it's not really come up to be fair sometimes people notice this scar, and thats usually how it comes up but otherwise.	Awareness of the scar and effect of self-image?
	R It sounds like the conversations do happen after noticing the scar, does that affect the relationship at all?	
	P No	
	R Ok thank you, would it be ok for me to ask about how you felt about your sexual experiences.	
	P Yes it's fine to ask.	
	R How do you perceive the impact on your sexual experiences following diagnosis and treatment?	
How medical teams helped	**P** (Silence 10 seconds) I don't think it made an impact to be fair. (Silence 5 seconds) maybe it's made me a bit more self-conscious about the scar but even then I'm not really fussed.	Awareness of the scar and effect of self-consciousness, but reassuring self that not bothered by others reactions
	R Did you have any concerns?	
	P Not really to be honest	Concerns managed at time by parents and

		clinicians?
	R OK with ideas around the scar, how did yourself perception change if at all?	
Being ‘psychologically strong – emotions seen as bad	**P** (Silence 10 seconds) I mean other than just noticing that there was a change within my body and I've had a testicle removed and a new one put in, (silence 3 seconds) no. You know I notice to change, I notice that it's not how I was born. No it's - my body image my personal body image hasn't really changed now.	Awareness of physical change. No sense of change in self-perception.
	R OK and do you mind me asking what your first sexual experience was like following diagnosis and treatment?	
	P It didn't come up in my sexual experience following, it was - it didn't come up with my partner at all actually - no wait it did but not, outside it came up, outside of the sexual encounter.	Conversations occurred outside of sexual encounter, not within.
	R Do you mean that was brought up by the other person?	
How medical teams helped	**P** No it was brought up by me. (silence 5 seconds). The actual sexual encounter, it didn't change anything and it didn't really change anything or alter the impact of the relationship. When it did come up with one person, it came up irrespective of any sexual encounter. With another person it came up because she notice it. But there is no relation to any scar, prosthesis it was as normal there were no concerns on my part or the other person.	Others become aware of scar but no issue. PS brought up scar/prosthesis and saw no negative impact.
	R OK so it sounds like there were no changes what about sex drive?	
	P No changes.	

	R Ok, do you remember what you were offered at the time in terms of support and since?	
How medical teams helped Sense of gaining from experience	**P** What was great, was really, really good, was every time I went to the Macmillan centre that was that room on the left, with the computers and people there, there's a pool table, it just felt very friendly and nice and I was really, really pleased that I wasn't on some ward and even just before I went for surgery there was the playroom - I know I was on the paediatric wards and that was about 18 I didn't really feel, I was still paediatrics technically kind of but I was actually so thankful I was there rather than on an adult ward. Psychologically I don't think anything, maybe that was because I was offered it and we denied it or it was forgotten to be given to us I don't know but nothing psychologically.	Sense of 'friendliness' of others – helped distract? Helped avoid thinking about it? Perception of being a child? Uncertainty over being offered psychological support or if this was refused at the time. Treatment decisions made by others
	R How do you feel about that now considering the possibility that you were either not offered or you weren't offered because you didn't need it?	
	P Fine actually (silence 5 seconds) I think maybe I'm just a psychologically strong person or just not in touch with my emotions laughs but I was fine about it	Awareness of emotional detachment – said in context of 'psychologically strong'
	R OK and how was your medical support?	
	P Really good and this is actually something I was thinking about today, before the surgery one of the registrars came and consented me for the surgery would I	Negative experience

		actually remember was he was particularly poor in his consenting he explained nothing, purely medical jargon and because obviously at the time I wasn't medically trained and so even to this day I still don't know what he was talking about he said something about not being able to feel my skin and I that's the only thing I remember that he told me because I remember being shocked about it and not really knowing what's going on but obviously I was 18 and I didn't know what surgery was. So that could have been better. I do appreciate that I was diagnosed and then within a week I was having surgery so that was great, so I appreciate the speed of the whole process (silence 5 seconds) erm oh and even the first time when I went to A&E at UCLH, well my dad took me after he had sort of had a moment to think about what to do and I remember the first guy he must be the junior doctor at A&E and he put a cannula in and said ‘how do you feel about all this? It must be quite stressful for you all?’ and I said ‘no it was fine’ but then I thought oh, maybe I should be thinking something, and he was very thing nice and I didn't think anything negatively of him.	when information not presented clearly – adds to uncertainty? Appreciation of the speed of diagnosis and then treatment. Possible awareness of emotional suppression at the time – a consideration of an alternative to this?
How medical teams did not help	**R**	It seems that you seem interested that these experiences stuck with you?	
	P	Yes exactly (silence 5 seconds) I think someone did the testicular ultrasound on the day and it was the classical NHS inefficiencies as there was no one to do an ultrasound and eventually they found someone to walk with me to a closed apartment and do it	Clinicians motivation to help seemed to alleviate distress. Previous positive medical experience has influenced current practice.

Reassurance from close others	(laughs) but peoples drives to try and help me maybe because they were young even now we have a young person on the ward who has cancer, we really tried to pull out all the stops for them but the medical sites was on the whole really, really good after the surgery they said we could send you home today or we can let you stay another day and at the time I was like I'll just stay here overnight and I was very happy about that and allowing me to do that which will I really liked I really appreciate it. Yeah. and you're asking what was the psychological support like for me? I think for my dad's especially, I'm not sure if there was anything, and I don't know if that's the point that's come up with other people, but my dad was moving GPs so he had to go off and print off all of the his medical notes and everything and I remember I was helping him with his notes and I was printing them somewhere and I remember seeing something about the consultation he had with his GP and that he's gone because he was upset about it and I think that he hadn't been offered anything and he hadn't brought up with me at the time and I remember that, but hit me just remember that. Yeah. **R** So it sounds like you're alluding to psychological support not necessarily for you but for those around you and that wasn't necessarily available? **P** Yes definitely and I think that may have helped at the time. **R** Is there anything else you can think of that may have helped at	Provided input on hospital experience regarding overnight stay seen favourably. Possible desire for psychological support for those around TCS. Guilt over distress of family?

	the time?	
Sense of gaining from experience Sense of gaining from experience	**P** (Silence 10 seconds) erm (silence 5 seconds) no. Maybe the only thing (Silence 5 seconds) because I only had one day of chemotherapy, if there was any side effects like ongoing vomiting which I did have, about how to get to the hospital. Obviously because it's in the congestion charge zone then you can't really drive in and but you can and stop outside and when you're coming this week to the nurse in charge about how to get to the hospital, because obviously it's better to go to the hospital you've been treated that because I have all your information, should I have ongoing vomiting I didn't really feel like it I didn't really need an ambulance, I was fine getting there ourselves but maybe I should have just called an ambulance I don't know but maybe the logistical side of things. But that's me clutching at straws so it was fine.	Practicalities of getting to hospital could have been improved.
	R Is there anything else you can think of that would have helped other than the situation that you've given.	
Sense of gaining from experience Desire to help	**P** (Silence 5 seconds) maybe a person like a nurse or clinical nurse specialist that I can call questions about anything. I think the issue I have at the moment is that if there are any questions doctor Stonehams nurse has changed a few times and I don't know if I've got the right number of I know who the right person is or having an e-mail address with someone I have the consultants email dress but you feel a bit like, you don't really want to bother the doctor all the time	Point of contact for questions and information not provided, but would have helped. Not wanting to burden consultant.

others through experience	(laughs) Maybe that would be useful.	
	R Ok, so what influenced your choice around prosthetics?	
	P (Silence 8 seconds) I remember I originally didn’t want one. I don't remember why I didn't want one, I thought it was strange just walking around with just one testicle, but my dad said to me that it would be good to have one and I was just like ‘OK cool.’ (Silence 10 seconds). Yup.	One testicle perceived as ‘strange.’
	R So it sounds like your dad influenced the decision. Were there any other influences?	
	P No not at all.	
	R And it sounded like you didn't want one initially but then you did have one. Is there anything else you can tell me?	
	P Yes but I actually I'm glad I did have one I'm glad I did listen to him I think if I didn't get it there would have been a chance I would have gotten one later down the line.	Happy with prosthetic.
	R OK you did touch on that but I just want to revisit what has made you want to engage or disengage with services?	
	P Medical and psychological? I guess I just wanted to be better, to be treated. My dad was a driving factor he said we needed to sort this quickly and get it treated quickly, also the efficiency of the service and how nice the Macmillan centre was and that was all amazing.	Speed of treatment helped with engagement. Parental support with engagement.
	R And was there anything that	

	made you want to disengage with services	
	P (Silence 5 seconds) that registrar just made me a bit, I was a bit angry with how he reacted and telling me what-was-what but, nothing else. Everything else was pretty good.	Anger at unfriendly, intellectualising staff.
	R That's fair enough, I'm just wanting to ask you now whether and how testicular cancer has changed how you feel about yourself.	
	P No (silence 5 seconds) I almost think it was a positive, you know I've been through something quite big, erm, the other people don't really go through and I've seen that I can deal with it and maybe that's to this day I'm quite to get up and go person I don't like to do nothing, maybe that's had an impact on how I am today. I like to have a purpose I think that's played a part in that.	Appreciation of 'unique' experience. Benefits of diagnosis and treatment: Increased sense of purpose and pragmatic attitude.
	R It sounds like that was different than pre diagnosis.	
	P Well pre diagnosis I was at school I wasn't really doing loads on the side and now I do loads on the side, (silence 5 seconds) you know we are trying to help people, I think that's the main thing I just want to try and help people and make sure that, well yeah, I just don't want to waste life I guess you can say I've become more pragmatic. I can't think if there's anything else to say (silence 10 seconds) I forgotten what it was.	Benefits of diagnosis and treatment: Increased physical activity. More positive outlook on life seems to have been adopted.
	R That's OK, is there anything else you think would be important to know that maybe we haven't	

	touched on. **P** Erm no, also I think is quite lucky that I had to, at the time, because when my a level results came through I think I got an A in biology or a star in geography a in biology being chemistry and I mean it's a next door in two ways and I looked but they university looks at it and they fought with everything that's been going on they've allowed you in I was only 1 and a half % off but I wasn't enjoying chemistry anyway so I think almost if I didn't have it I maybe I wouldn't be a doctor today and maybe they wouldn't have let me in. Yeah it's almost been the positive on my life, has had a positive impact I think. **R** It sounds like you have been able to take value from it and anyway that you could. **P** Yes absolutely. **R** Is there anything else you think would be important to know. **P** No I just think that everything that you're doing is incredibly important. **R** Thank you very much.	TC seen as advantageous to some personal goals. Appreciation of bettering experience for others.

Appendix I: Example organising David's Exploratory notes into Experiential Statements.

	Experiential Statements	Subthemes
1	Being 'psychologically strong – emotions seen as bad	• Awareness of emotional detachment – said in context of 'psychologically strong' • Emotional detachment helped disclosure? • Emotional detachment? • Emotional expression alluding to 'not being me'. • Emotions seen as getting in the way? • Exams as a distraction from reality? • Intellectualising as an attempt to numb emotions? • Inviting emotion would have been a hindrance? • Naturalistic setting alleviated shock. • No longer thinking about it - Sense of having moved on? • No sense of emotional response from diagnosis. • Perception of being a child? • Possible awareness of emotional suppression at the time – a consideration of an alternative to this? • Sense of keeping calm after diagnosis. • Sense of no distress now during diagnosis • Concern over inviting emotions in others diagnosed in similar situation seen as bad. • Awareness of emotional detachment – said in context of 'psychologically strong' • Intellectualising as an attempt to numb emotions? • Inviting emotion would have been a hindrance. • No sense of emotional response from diagnosis.
2	Delaying processing until later	• Delayed making sense of it until it was over? • Memories returning through prompting • Did not consider certain treatments as 'treatment' at the time, even as David is an MD. • Exams as a distraction from reality? • No longer thinking about it - Sense of having moved on? • Struggle to remember, result of emotional detachment? • Suppressing memory?
3	Solution focussed approach	• Maintaining a pragmatic approach. • Benefits of diagnosis and treatment: Increased sense of purpose and pragmatic attitude • Switching off emotions helped when being diagnosed, helped with being pragmatic? • Pragmatic adoption? • Struggles to say the word cancer. Unprocessed? Evokes anxiety? Unconscious sense of thought/action fusion?
4	Struggling to say certain	• 'It' described, not testicular cancer. • Able to mention testicle when discussing clinicians, sign

	words	of personal detachment? • Unsure of mechanism around being unable to say the word.
5	Reassurance from close others	• Appreciation of bettering experience for others. • Desire to eliminate stigma and make it less awkward to others. • Desire to help others in similar situation. • Desire to improve others experience of it. • Desire to raise awareness. • No sense of obligation to tell people. Idea that it can be concealed from others. • Not wanting to burden consultant. • Parental support with engagement. • Presence of close family. • Others become aware of scar but no issue. • PS brought up scar/prosthesis and saw no negative impact. • Strengthened relationships with those actively caring, weakened with those whom did not react in this way. • Family were supportive? • Immediate family have knowledge to help and support. • Sense of ‘friendliness’ of others
6	How medical teams helped	• Appreciation of the speed of diagnosis and then treatment. • Awareness that speakers approach and gender were important in conveying the ‘right’ type of message? • Clinicians motivation to help seemed to alleviate distress. • Consultants humanity helped David trust her judgment. • Context sensitive clinicians helped with intimate topics when parents were around. • Full trust in consultants treatment decisions? Was father not involved? Did he also fully trust consultant? • Accidental disclosure from nursing staff, but taken well by David. • Practicalities of getting to hospital could have been improved. • Professionals feeling confident in the discussion made it easier? • Provided input on hospital experience regarding overnight stay seen favourably. • Treatment decisions made by others • Speed of treatment helped with engagement. • Slight embarrassment with intimate convo, offset by professionalism of staff. • Uncertainty over being offered psychological support or if this was refused at the time.
7	How medical teams did not help	• Anger at unfriendly, intellectualising staff • Negative experience when information not presented clearly – adds to uncertainty

		• Point of contact for questions and information not provided, but would have helped. • Resentment towards pre-existing experience of TC and checking.
8	Complications arising from close others	• Concerns managed at time by parents and clinicians? • Friendships ending following their negatively perceived reaction to disclosure. • Guilt over distress of family? • Telling others equated to announcing it on a pedestal (to a degree). • Uncertainty as to the reaction in others. Increased anxiety in disclosure? • Perhaps flatmate is not a close friend? Therefore no disclosure?
9	Concerns for the future regarding self	• Appreciation of the negative reaction of others would have contributed to negative impact. • Awareness of physical change. • Awareness of the scar and effect of self-consciousness, but reassuring self that not bothered by others reactions • Awareness of the scar and effect of self-image? • Happy with prosthetic. • Conversations occurred outside of sexual encounter, not within. • No sense of change in self-perception. • One testicle perceived as ‘strange.’ • Non-disclosure of prosthetic to close friends – shame? Embarrassment? • Non-disclosure of spermbanking to others – shame? Embarrassing? Unnecessary detail?
10	Desire to help others through experience	• Idea of individualising manner in which you tell someone. • Alluding to men sharing experience? • Possible desire for psychological support for those around TCS.
11	Sense of gaining from experience	• More positive outlook on life seems to have been adopted. • Appreciation of ‘unique’ experience. • Benefits of diagnosis and treatment: Increased physical activity. • Previous positive medical experience has influenced current practice. • TC seen as advantageous to some personal goals.

Appendix J: Example Organisation of David's Experiential Statements into Personal Experiential Themes.

Personal Experiential Statement	**Experiential Statements**
Detaching emotionally	Being 'psychologically strong – emotions seen as bad, Struggling to say certain words,
Adoption of pragmatic approach	Solution focussed approach, Delaying processing until later, How medical teams did not help,
Not wanting to worry others	Reassurance from close others, Complications arising from close others,
Trust in medical professionals	How medical teams helped, How medical teams did not help,
Increased self-consciousness	Concerns for the future regarding self, Complications arising from close others,
Inspiration	Sense of gaining from experience, Desire to help others through experience,

Appendix K: Example Organisation of Personal Experiential Themes in to Group Experiential Themes.

Global Experiential Themes	Personal Experiential Themes
Dealing with the shock	Detaching emotionally, Adoption of a pragmatic approach, Downplaying severity of testicular cancer, Seeing cancer as a test or challenge, Avoidance of specific aspects, Difficulty in saying specific words,
Fear and weight of responsibility	Treatment responsibility remaining with clinicians, Avoidance of hearing treatment options, Decisions surrounding prosthesis, Requirement of immediate answer to questions,
Reassuring those closest to me	Helping to manage anxiety of others, Burden of reassuring others, Not wanting to worry others,
Development of ‘who I am’	Sense of inferiority, Worries around future romantic partners, Feeling different, Detachment of body from mind, Presence of prosthetic
Sense of faith	Disclosure to others Trust in medical professionals Trust in prosthesis
Feeling of transformation	Inspiration

	Personality change, Strengthening personal relationships, Angry at self, Increased self-consciousness, Anxiety over reoccurrence

Appendix L: Abridged Bracketing interview

Bracketing Interview – Pre-Analysis Questions

1. What are my interests in this research?

Interested in research surrounding development of complex concepts such as psychosexual identity – stemming from balancing Arabic concepts of masculinity with more westernised concepts. Found MRP option incredibly interesting and challenging. Also found qualitative approach personally challenging as bulk of prior research experience quantitatively focussed. Some personal interest as I have known friends with concerns of testicular health which turned out to be non-cancerous and did not require treatment. Interested in the support offered at such a critical period in peoples lives surrounding age but also the diagnosis and treatment at this age.

2. What are my personal issues in undertaking this research?

The associations and stereotypes of cancer, including the assumption that cancer is lifelong and rarely is overcome in a ‘final’ manner - although an awareness that this does happen possibly more than I am ‘exposed’ to. Speaking to supervisor about prognosis rates for testicular cancer was enlightening and helped manage these unconscious stereotypes, but an appreciation that different people may have different experiences with their diagnosis and a completed ‘treatment’ may have long lasting physical and psychological effects (or not). An awareness that the majority of oncology staff may be female, thus a male interviewer may have some impact on the participants and what this may bring up for both. This includes possible difficulties with divulging information regarding possible feeling of vulnerability due to cultural masculine expectations – particularly as I am a bearded male which participants may perceive as ‘typically’ masculine.

3. Where does the power belong in my research project and where do I belong in that hierarchy?

An unconscious balance of power may tip towards me due to my being the researcher, potentially perceived as an ‘expert’ by participants, and likelihood that I have not undergone diagnosis and treatment for testicular cancer. Participants will hold power surrounding the quantity and quality of information they divulge, however the researcher is orchestrating the interview which places me in a ‘leader’ type role. No compensation for engaging in the research is to be offered, so the hope that participants engage in a potentially emotive interview with the motivation to help others. Supervisors hold clear power over lead researcher due to extensive knowledge of subject area and research methodologies, thus their advice appears paramount to creating ‘good’ research.

4. What are my personal values and what may impact me subjectively?

Personal family experience of medical care when under 18 involved family systems arguing amongst themselves and with medical professionals, leading to feelings of guilt in myself. An awareness that this experience may be shared by participants, however considering the complexity of testicular cancer this may not be the case and family systems may be more supportive. Participants divulging experiences that are different to mine may evoke feelings of warmth and happiness for them, and potentially increase resentment towards my own parents.

5. Could my role provide any conflict?

Lack of discomfort in dealing with anger and aggression due to professional background working in highly emotive mental health services. Lack of discomfort in addressing risk of harm to self concerns due to extensive experience of risk assessments. Concerns that initial contacting of potential participants may evoke fear in them as initial concerns may be that I am calling with ‘bad news’ surrounding their previous diagnosis and treatment. Findings may be perceived negatively by health professionals as it may highlight shortcomings in treatment. One supervisor is a consultant and knows the participants so this may impact their future relationship.

6. Any lack of neutrality?

Lack of engagement from participants may give rise to frustration, particularly with how long it has taken to arrange data collection. Participants who give short answers may evoke worry as there is a sense the data should be rich. Stress if the interviews appear too short or abstract without the participant able to clarify certain points. Unclear responses from participants may make managing the interview challenging. Concern over whether self-disclosure come up and will this be an issue? Potential for me to probe more in areas the participant does not want to/feel able to divulge in and this causes a rupture in the interview.

Appendix M: Abridged research Diary

Entry 1

Data collection is due to start soon, it has taken a very long time and been a source of considerable stress in me. I hold anger towards UCLH Information Governance for delaying RND approval of my research for six months. I wondered if my eagerness to complete the research may impact the quality of the interviews, however I reminded myself that this is how it feels now, and when interviews can start this worry may be unwarranted due to an appreciation that I can collect data. Thus I will do so thoroughly.

Entry 2

Data collection can formally begin and I am ecstatic! Within the same week I have a list of participants I can contact. Some have already been booked in now and I am elated with the speed this is now moving in. This also reminds me of my resentment towards Information Governance but I am postponing those emotions until after the research is completed. I have a participant who has returned the consent form booked in for tomorrow and I am anxiously excited to conduct this interview.

Entry 3

I have completed two interviews now and although both provided rich and quantiful information, I am aware that the interviews were both around 30 minutes. I am aware of my anxiety surrounding this as an hour was predicted to be the average interview length. After demonstrating and discussing the transcript with supervisors, I was reassured and reminded of what now seemed quite obvious – the participants spoke very quickly and did not appear to hold anything back. They readily divulged information in a manner which was likely catching me off guard as I was expecting the interviews to be more emotive. Although this may be the case with the remainder, it is good to remind myself that people are different, including their reactions and appraisals. Interviews may be long or short but this does not necessarily mean the data obtained is not rich and full of analytic potential.

Entry 4

I am noticing a large number of similarities within the participants, particularly surrounding supportive family and friend systems. I find this heart warming and although I was initially concerned that I would feel more resentful towards my own parents, that does not seem to be the case. I am able to appraise the complexity and anxiety associated with a close family member receiving a scary diagnosis and acknowledge again that people react differently. The warmth I am feeling is not inhibiting my ability to conduct the interviews, I am able to probe in to the positive aspects as well as the negative aspects without judgment.

Entry 5

Participants all speak to fondly of UCLH oncology and their experiences with one of the researchers on this project. I am noticing vicarious pride in the consultants clinical demeanour but wonder if they agreed to take part because of the positive alliance. Perhaps participants without a positive experience were unwilling to take part in research? Would their experience provided new perspectives and themes?

Entry 6

The final interview has concluded, and I finished the transcript this evening. I feel a strong sense of pride and a justified exhaustion in the work I have been carrying out these last few weeks. Although I am keenly aware that the end is still a way off, as the thorough and lengthy analysis must take place alongside other university responsibilities.

Entry 7

Harris was unable to say certain words during his interview. Perhaps ‘unable’ isn’t the correct way to describe it, but after reviewing and annotating his transcript multiple times, I became aware that he did not say certain words and instead alluded to them. I was aware that this was missed during the interview. I do remember the same for Daniel, however he expressed an awareness of a difficulty in saying certain words. I find myself wondering if this is a common theme amongst other participants.

Entry 8

Although it was evident during the interviews, not all participants received a prosthetic. I wondered about myself if I was in their position, whether or not I would have accepted an implant. I then identified with Richter in that perhaps the decision would not have been mine to make, but my parents, who would have refused it due to their own perceptions and beliefs and irrespective of my wishes. I noted my resentment towards my parents increase, and although I was not in this particular position, I did find myself in situations where my parents wishes and desires were often placed in front of my own when it came to situations concerning me.

Entry 9

Themes have been discussed with Max, who noted his surprise that his experience aligned with the participants. He described a sense of feeling he was alone in his experience, and that his appraisals and the meanings made from his experience were previously believed to be ‘unique’. He thanked me for involving him in the research, which I seemed to return with a thanks for helping to support this research and make it happen. It seemed I felt unable to sit with his gratitude, instead feeling it should be returned.

Entry 10

The themes were discussed with my two supervisors, and the comments and suggestions were exceptionally helpful. I fee empowered in creating research that is relevant and may help guide future treatments of people diagnosed and treated during adolescence. I was aware of the sense of dread in how much more work needed to take place.