

VANDERBILT UNIVERSITY



School of Nursing

Body Image and Sexuality Research in Head and Neck Cancer

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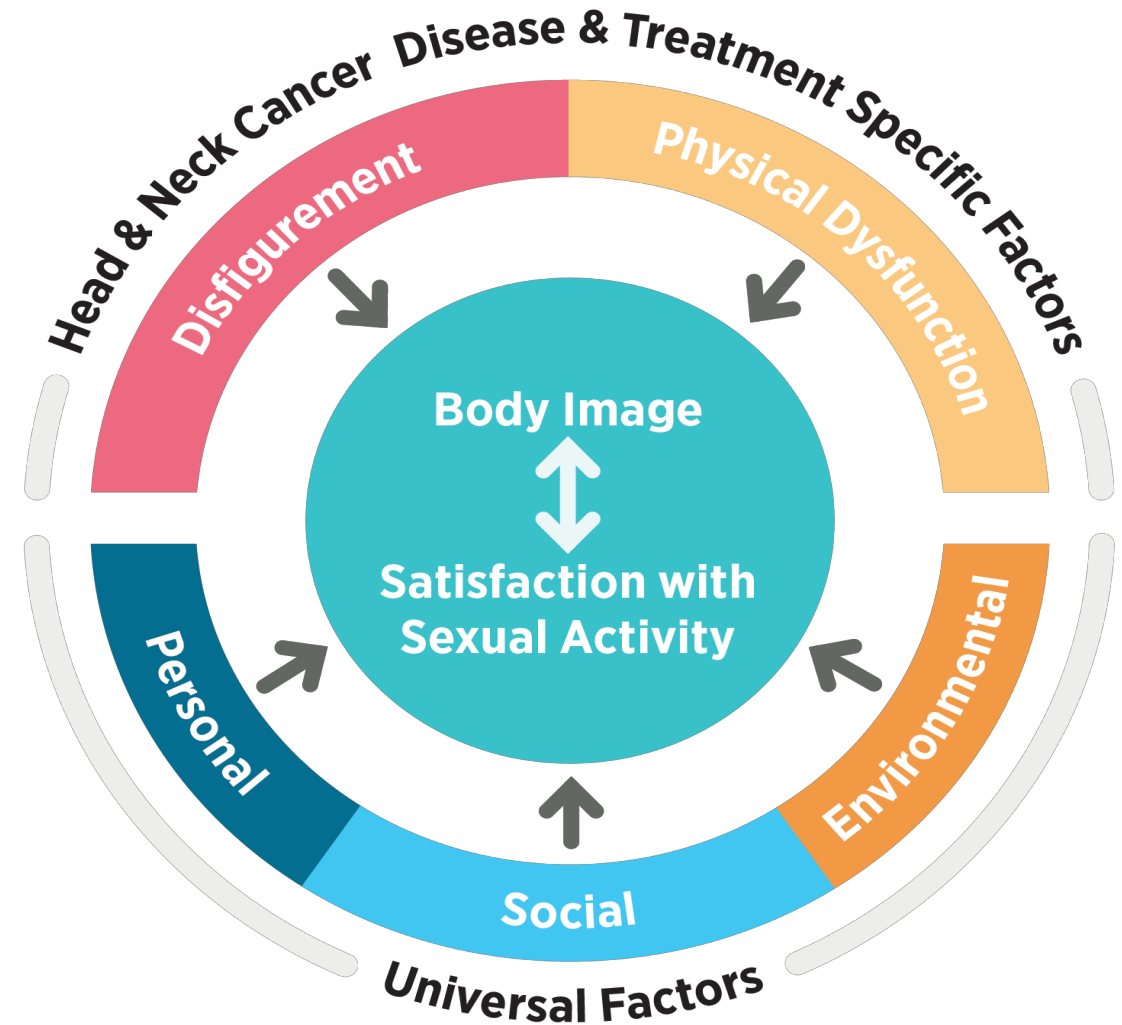


Overview of Presentation & Learning Objectives

- ▶ Describe the latest evidence detailing the impact of head and neck cancer (HNC) and its treatment on body image and sexuality.
- ▶ Describe measurement of body image and sexuality in HNC research
- ▶ Describe the state of intervention research in this area
- ▶ Identify important research gaps

Body Image and Sexuality

- ▶ Body Image – how an individual feels about the way they look and function
- ▶ Sexuality – an individual's experience of sexual activity and sexual satisfaction





State of the Science

- ▶ **Rhoten BA, Murphy B, Ridner SH (2013)** Body image in patients with head and neck cancer: a review of the literature. *Oral Oncology*. 49(8):753-760.
<https://doi.org/10.1016/j.oraloncology.2013.04.005>
— Cited by 60

- ▶ **Rhoten BA (2016)** Head and neck cancer and sexuality: a review of the literature. *Cancer Nursing*. 39(4):313-320.
<https://doi.org/10.1097/NCC.00000000000000289>
— Cited by 12



Search Strategy

► Body Image and Head and Neck Cancer

- ("head and neck neoplasms"[MeSH Terms] OR ("head"[All Fields] AND "neck"[All Fields] AND "neoplasms"[All Fields]) OR "head and neck neoplasms"[All Fields] OR ("head"[All Fields] AND "neck"[All Fields] AND "cancer"[All Fields]) OR "head and neck cancer"[All Fields]) AND ("body image"[MeSH Terms] OR ("body"[All Fields] AND "image"[All Fields]) OR "body image"[All Fields]) AND ("2009/05/19"[PDat] : "2019/05/16"[PDat])
- 337 (abstract review) → 55 (full text review) → 32 (final sample)

► Sexuality and Head and Neck Cancer

- ("head and neck neoplasms"[MeSH Terms] OR ("head"[All Fields] AND "neck"[All Fields] AND "neoplasms"[All Fields]) OR "head and neck neoplasms"[All Fields] OR ("head"[All Fields] AND "neck"[All Fields] AND "cancer"[All Fields]) OR "head and neck cancer"[All Fields]) AND ("sexuality"[MeSH Terms] OR "sexuality"[All Fields] OR "sexual behavior"[MeSH Terms] OR ("sexual"[All Fields] AND "behavior"[All Fields]) OR "sexual behavior"[All Fields]) AND ("2014/05/18"[PDat] : "2019/05/16"[PDat])
- 109 (abstract review) → 26 (full text review) → 22 (final sample)



Empirical Studies (n=29; 13 body image; 16 sexuality)

Body Image		Sexuality	
Intervention Research			
n=2 Chen et al 2017 Brake et al 2014		n=1 Hoole, Kanatas, & Mitchell 2015	
Descriptive Research			
<i>Body Image Focus</i> (n=8) Teo et al 2016 Chen et al 2015 Lee et al 2015 Clarke et al 2014 Rhoten et al 2014 Fingeret et al 2012 Flexen et al 2012 Fingeret et al 2010	<i>Broader Focus (n=3)</i> Nixon et al 2018 Wulff-Burchfield et al 2018 Airoidi et al 2011	<i>Sexuality Focused (n=5)</i> Melissant et al 2018 Akil et al 2017 Batioğlu-Karaaltın et al 2017 Taberna et al 2017 Rogers et al 2015	<i>Broader Focus (n=10)</i> So et al 2019 Bozec et al 2018 Bui et al 2018 Jansen et al 2018 He et al 2017 Mair et al 2017 Obrien et al 2017 Suzuki et al 2016 Egestad-Nieder 2015 Offerman et al 2015



Other Publications (n=25; 19 body image; 6 sexuality)

Body Image	Sexuality
Case Study: n=1; Hendricks-Ferguson 2016	
Protocol: n=1; Turner et al 2014	
Measurement-Focused	
n=6 Rodriguez et al 2019; Ellis et al 2019; Melissant et al 2018; van Leeuwen et al 2018; Jean-Pierre et al 2013; Deno et al 2011	n=3 Hoole et al 2018 Jansen et al 2016 Hoole et al 2015
Reviews	
n=8 Davidson & Williams 2019; Qualizza et al 2018; Alias & Henry 2018; Fingeret et al 2014; Rhoten et al 2013; Semplet et al 2013; Moussas et al 2012; Pandian 2012	n=1 Rhoten 2016
Education	
n=1; Foulkes 2013	
Commentary/Editorials	
n=2 Rousseau 2013; Ephros 2010	n=2 D'Souza et al 2017; Ratanski et al 2017



Body Image & Head and Neck Cancer – Measurement

Current Utilization in Research

- ▶ Adapted Satisfaction with Appearance Scale
- ▶ Appearance Schemas Inventory-revised**
- ▶ Derriford Appearance Scale-24&59
- ▶ Body Image Coping Strategies Inventory
- ▶ Body Image Disturbance Questionnaire**
- ▶ Body Image Quality of Life Inventory
- ▶ Body Image Scale**
- ▶ Body Image Survey (HN specific)
- ▶ Body Satisfaction Scale
- ▶ Fear of Negative Appearance Evaluation Scale**
- ▶ Head and Neck Scale – Appearance Subscale
- ▶ Multidimensional Body-Self Relations Questionnaire
- ▶ Quality of Life Measures
 - EORTC QLQ C30 and HN35
 - FACT-HN
 - Patient Concerns Index
 - UW-QOL



Body Image & Head and Neck Cancer – Measurement

- ▶ Appearance Schemas Inventory-Revised
 - Cash, Melnyk, & Hrabosky 2004
 - 20 items
 - Self-evaluative salience
 - Motivational salience
 - <http://www.body-images.com/assessments/asi.html>



Body Image & Head and Neck Cancer – Measurement

- ▶ Body Image Disturbance Questionnaire
 - Cash et al 2004
 - 7 scaled items
 - Preoccupation with appearance-related concerns
 - Distress and impairment in function
 - Behavioral avoidance
 - <http://www.body-images.com/assessments/bidq.html>



Body Image & Head and Neck Cancer – Measurement

- ▶ Body Image Scale
 - Hopwood et al 2001
 - 10 items
 - Satisfaction with appearance related changes associated with cancer treatment
 - Affective, behavioral, and cognitive domains
 - <https://www.ncbi.nlm.nih.gov/pubmed/11166145>



Body Image & Head and Neck Cancer – Measurement

- ▶ Fear of Negative Appearance Evaluation Scale
 - Lundgren, Anderson, & Thompson 2004
 - 6 items
 - Apprehension about appearance evaluation
 - <https://www.ncbi.nlm.nih.gov/pubmed/15000956>



Body Image & Head and Neck Cancer – Measurement

Opportunities for Future Utilization

- ▶ McGill Body Image Concerns Scale - HNC
 - Rodriguez et al 2019
 - 21 items
 - Social discomfort
 - Negative self-image

Body Image & Head and Neck Cancer – Descriptive Research

Cross-sectional Studies

- ▶ HNC patients undergoing surgery have body image concerns both pre- and post-procedure.
 - Teo et al 2016; Chen et al 2015; Fingeret et al 2012; Fingeret et al 2010
- ▶ Body image concerns affect 33-75% of patients.
 - Airolidi et al 2011; Fingeret et al 2012
- ▶ Body image concerns are associated with a variety of:
 - Behaviors
 - Decreased smiling intensity
 - Speaking less
 - Social avoidance as a coping mechanism
 - Characteristics
 - Younger age
 - Female gender
 - Advanced tumor stage
 - Oropharyngeal carcinoma
 - Comorbidities
 - Depression
 - Reduced functional well-being
- Nixon et al 2018; Chen et al 2015; Lee et al 2015; Flexen et al 2012; Fingeret et al 2010

Body Image & Head and Neck Cancer – Descriptive Research

Longitudinal Studies

- ▶ Rhoten et al 2014
 - Body image significantly higher at 12 weeks-post treatment than at end of treatment and 6-weeks post-treatment
 - Body image and depressive symptoms significantly associated

- ▶ Clarke et al 2013
 - No significant differences in body image from baseline (at least six months after treatment) and nine months after baseline.

Body Image & Head and Neck Cancer – Intervention research

Cosmesis-focused

- ▶ Chen et al. (2017).
 - 4 session skin camouflage training program
 - Intervention participants greater improvement in body image than control group

- ▶ Brake et al. (2014).
 - Post-treatment liposuction for submental lymphedema
 - Self perception of appearance significantly improved from pre to post procedure



Sexuality & Head and Neck Cancer - Measurement

Current Utilization in Research

- ▶ EORTC QLQ H&N35
 - During the past week:
 - *Have you felt less interest in sex?*
 - *Have you felt less sexual enjoyment?*
- ▶ FACT-H&N; FACT-NP
 - *I am satisfied with my sex life.*
- ▶ Arizona Sexual Experiences Scale
 - During the past week:
 - How strong is your sex drive?
 - How are you sexually aroused?
 - M only: Can you easily get and keep an erection?
 - F only: How easily does your vagina become moist or wet during sex?
 - How easily can you reach an orgasm?
 - Are your orgasms satisfying?
- ▶ modified Sexual Adjustment Questionnaire
 - *What is the importance of sexual activity in your life?*
 - *Do you enjoy sexual activity?*
 - *Do you have a desire for sexual activity?*
 - *Do you feel satisfied after sexual activity?*
 - *How often do you have sexual activity?*
 - *Are you satisfied with the frequency of sexual activity in your life?*
 - *Have you been the one to initiate sexual activity with your partner since your last cancer treatment?*

Sexuality & Head and Neck Cancer - Measurement

Opportunities for Future Utilization

- ▶ MHK Questionnaire (Hoole et al 2018)
 - 22 items
 - Problems with intimacy after dx/tx of HNC
 - HNC-specific issues that may affect desire for intimacy

- ▶ EORTC QLQ-SHQ22
 - 22 items
 - Sexual health and cancer
 - Phase IV of development

Sexuality & Head and Neck Cancer – Descriptive Research

Cross-sectional Studies

- ▶ Sexuality is one of the highest unmet supportive care needs among HNC survivors.
 - So et al 2019; Jansen et al 2018
- ▶ Sexuality is under addressed in clinic notes
 - Rogers 2015
- ▶ Patients who have had a total laryngectomy have significantly more sexual problems than those having had a partial laryngectomy
 - Akil et al 2017; Batiog et al 2017; Offerman et al 2015
- ▶ Reduced sexuality is associated with depression
 - Obrien et al 2017; Suzuki et al 2016

Sexuality & Head and Neck Cancer – Descriptive Research

Longitudinal Studies

- ▶ Sexuality is significantly impaired without return to baseline.
 - Bozec et al 2018; Melissant et al 2018; Bui et al 2018; Taberna et al 2017; Mair et al 2017
- ▶ Poorer sexuality outcomes are associated with:
 - Older age
 - Trouble with social contact / poor social functioning
 - Weight loss
 - Constipation before treatment
 - Female gender
 - Total laryngectomy
 - Poor nutritional status
 - BMI > 25
 - Melissant et al 2018; Bui et al 2018; He et al 2017; Egestad-Nieder 2015

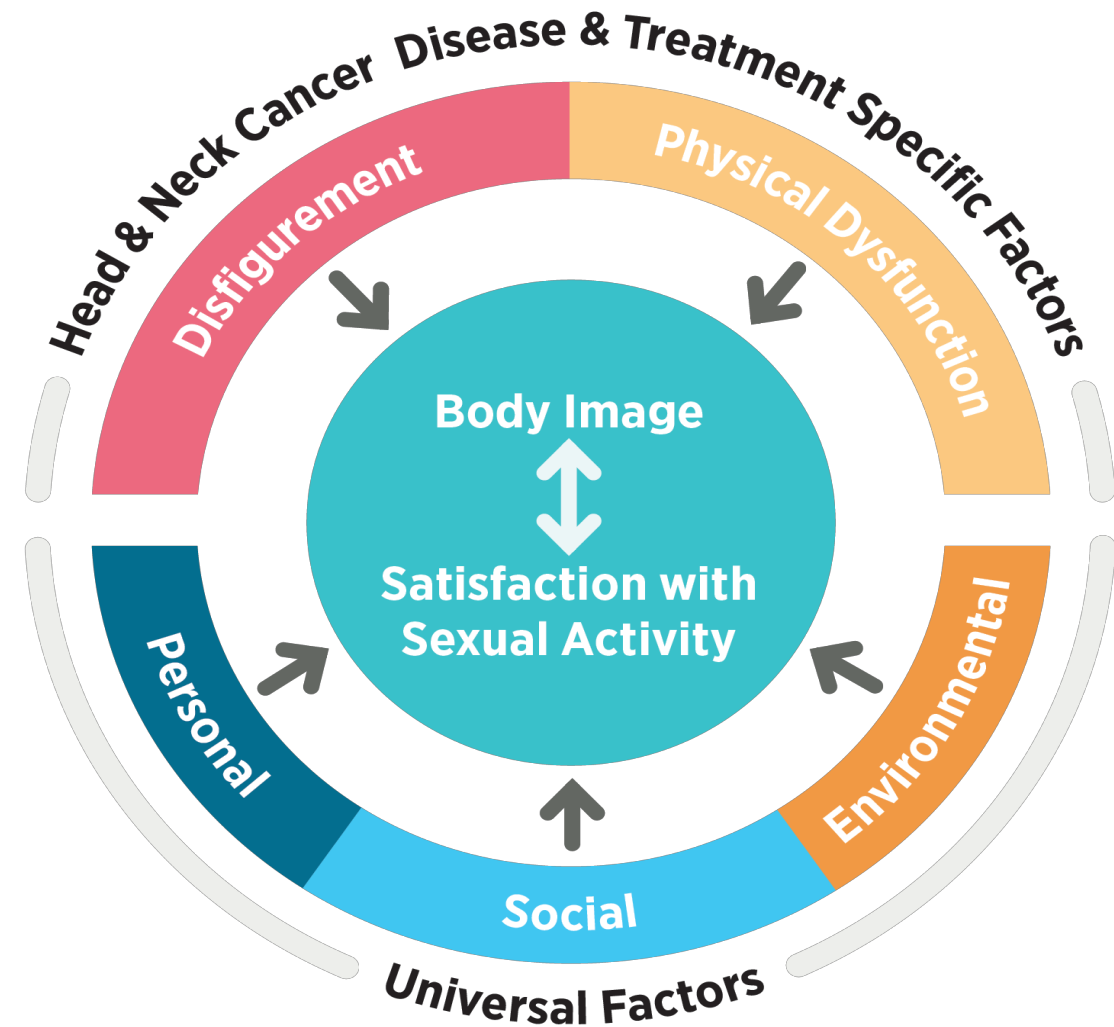
Sexuality & Head and Neck Cancer - Intervention Research

- ▶ Hoole, Kanatas, & Mitchell. (2015). Psychosexual therapy and education in patients treated for cancer of the head and neck. *British Journal of Oral and Maxillofacial Surgery*, 53: 601-606.
 - Introduce strategies for diagnosis and treatment of psychosexual problems
 - Describe early experiences of use
 - Brief narratives and case reports

- ▶ Intervention development and formal testing is lacking at this time.

Summary

- ▶ Body image and sexuality issues are problematic for some, if not many patients with head and neck cancer.
- ▶ These issues do not end after completion of treatment and may be more salient to a patient as time elapses.
- ▶ In order to meaningfully assess body image and sexuality in this population, self-report measures should provide both clinically actionable and research-applicative information.



Important Research Gaps

- ▶ Intervention Research
 - Population and patient characteristic tailoring
 - Psychosocial focus
 - Practical, real world examples
- ▶ Addressing concerns of patients who are not partnered
- ▶ Addressing concerns of patients who identify LGBTQ+



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