# Body image in head and neck cancer patients - Schilder's conceptual framework revisited

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# ABSTRACT

# Background

Disfigurement and dysfunction of the face are attributes of body image disturbance in individuals with head and neck cancer. Research in body image has highlighted that people with head and neck cancer experience significant disfigurement and dysfunction with altered body image disturbance.

Although research has advanced our understanding and knowledge of the characteristics of body image and body image disturbance, there is a lack of focus on the theoretical frameworks that interrogate the body image construct in individuals with head and neck cancer and the role of the face in formulating this construct.

# Aim

This paper aims to appraise body image conceptual frameworks with an emphasis on the face as an integral organ in formulating body image.

### Methods

Schilder's seminal body image conceptual framework was appraised and contrasted with that of Kolb's and Price's model as well as with the current evidence on body image disturbance in relation to the face.

## **Findings**

Body image conceptual frameworks are valuable tools for understanding body image and body im-

age disturbances in individuals with head and neck cancer. However, Schilder's framework integrates the physiological, psychological and sociocultural aspects the body image.

### Conclusion

Schilder's framework embodies body image and enables an integrated and inclusive approach to body image in individuals with head and neck cancer.

# INTRODUCTION

Body image (BI) is the dynamic perception of one's own bodily appearance, function and sensations and the feelings associated with these perceptions. <sup>1,2</sup> It is a multifaceted construct that is influenced by neurocognitive, psychosocial, physiological, cultural and pathological factors. <sup>3,4</sup>

Head and neck cancers (HNC) comprise a heterogeneous group of malignancies in various anatomical subsites, including the oral cavity, pharynx, paranasal sinuses, nasal cavity, larynx and salivary glands.<sup>5,6</sup> HNC constitutes 3% of all malignancies diagnosed in the United States and the United Kingdom<sup>5,7</sup> and has significant morbidity, with a mortality rate of 16%.<sup>7</sup>

The treatment modalities for HNC involve ablative surgery with or without adjuvant therapy (i.e., chemotherapy and radiotherapy). The morbidity associated with HNC 9 causes significant disturbances of BI. 10 Unlike neoplasms occurring in other organs,

head and neck neoplasms are psychologically devastating, due to their visibility<sup>11</sup>; as a result, BI theories have become valuable frameworks for understanding the BI and body image disturbances (BID) among this group of patients. This review explores Schilder's seminal conceptual framework of BI, examines the significance of the face in relation to BI and the implications of BID of the face. The application of the BI framework and BID are discussed in relation to individuals with HNC.

# Conceptual Framework: Body Image

A number of conceptual frameworks for BI have been proposed<sup>3,4,12,13,14</sup>, reflecting the challenges and complexities inherent with the BI construct. However, research has paid only limited attention to Schilder's model as a framework for BI in individuals with HNC. This discussion will focus on Schilder's model (1950)<sup>3</sup>, contrasting it with Kolb's model (1975)<sup>14</sup> and Price's BI care model (1990).<sup>13</sup> There is an increasing recognition of BID in individuals with HNC<sup>15</sup> or other physical diseases.<sup>4</sup> Schilder's model attempts to elucidate and interrogate the influence of the various elements of BI in such individuals and thus has the potential to be applied in an oncology setting.

# Schilder's conceptual framework of BI

Schilder's conceptual framework of BI<sup>3</sup> is grounded in Head's postural model of the body<sup>16</sup> and explores domains that he referred to as physiology, the libidinous structure and sociology of BI. In Schilder's opinion, these reflected the construction of an individual's BI. Whilst Schilder did not define BI explicitly, there is an assertion that his definition of BI is embodied in the opening sentence of his book<sup>17</sup>:

The image of the human body means the picture of our own body which we form in our mind.<sup>3,pg</sup> <sup>11</sup>

He also argued that BI is not a mere sensation or imagination, as it also encompasses experiences that are stored in the cerebral cortex but are not necessarily part of one's central consciousness; further including our personalities and emotions influence our BI. He also contended that BI is a dynamic construct characterised by perpetual inner self-construction and self-destruction.<sup>3,pg15</sup> As a tri-dimensional construct, Schilder explored the physiological basis of BI, including its libidinous structure and sociological aspects. Additionally, he proposed that BI begins to develop in utero and changes throughout the indi-

vidual's life.<sup>3,pg105</sup> therefore, BI is a dynamic construct. He maintained that the aforementioned three facets contribute to BI development in a parallel, simultaneous, yet interactive and reciprocal fashion. Schilder described how, physiologically, the sensory and motor systems and the face (as well as other organs) facilitate physiological function and people's interactions with the world (social function). The libidinous structure of BI entails, for example, the love for oneself and the formation of the personality (ego), which is formed through tactile sensations and the psychogenic impressions thereof.

Although scholars of BI do not make direct inferences to Schilder's model, the model remains contemporaneous with current views of BI. An extensive body of knowledge affirms that BI is a dynamic multidimensional construct, as Schilder proposed. Furthermore, there has been a paradigm shift wherein the functionality of the body (or dysfunctionality), as opposed to the emphasis on the physical appearance of the body, is recognised as an integral element of BI. 15,19 Interestingly, Thompson<sup>20</sup> was of the opinion that an inclusive and integrated framework is required. He also proposed the biopsychosociocultural framework, which has elements similar to those proposed by Schilder.<sup>3</sup>

People with HNC have numerous BI concerns that include perceptions and emotions related to altered physical appearance and functionality<sup>21</sup> and challenges with social adjustment post-treatment.<sup>15</sup> Thus, Schilder's model highlights the role of physiological, psychological and sociocultural elements that could potentially influence the development of BID in people with HNC.

# Kolb's model of body image

Like Schilder's work, Kolb's model is also built on Head's work. <sup>16</sup> Kolb<sup>14</sup> proposed that body percept should be a term associated with BI, as observed from a neurological perspective. Body percept entails the sensory integration of past and present sensory experiences of the body in the sensory cortex. In contrast to Schilder's tri-dimensional construct, Kolb's construct of BI has two attributes: the body percept (physical body) and body concept (cognitive and emotive elements). The body concept includes a person's thoughts, feelings, attitudes and memories and evolves as the individual (the ego) views and experiences their body with others. The body ego is the perceiving aspect of the personality as it concerns the

BI, while the body ideal reflects how the individual measures the idealised precepts and concepts held of his or her body. The ego functions to integrate the disparities within the evaluations, which lead to arousal of either painful or pleasurable affect. In contrast to Schilder, Kolb's model emphasises the relationship between the somatosensory perception of the body and the cognitive—behavioural response mediated by the ego (personality). Whilst Schilder had an integrated approach and recognised the importance of the various domains in the construction of BI, Kolb posited that kinaesthetic and tactile sensations are the primary domains, and optic or olfactory sensory perceptions are secondary domains.

Kolb suggested that BID occurs within the context of the personality (ego). Thus, any disfigurement, as is the case with HNC patients, will result in a personality change. He proposed that it is the plasticity of an individual's personality that may inadvertently result in a healthy or pathological psychological response. He argued that poor adaptation manifests as various psycho-pathological responses or behaviours to alter BI. An example of this is the denial of the disfigurement, which can result in an individual being less compliant with treatment. Evidently, individuals with HNC often have maladaptive coping strategies such as denialism, self-blame and behavioural disengagement. <sup>22,23</sup>

# Price's model of body image

Price's model<sup>13</sup> is comprised of three components, which he argued must be in equilibrium for an individual to have a satisfactory BI. The body reality refers to the body's physical existence with its genetically predetermined traits. The body ideal is the picture in our heads of how we would like the body to look; this is influenced by societal and cultural norms, the media and changing attitudes towards fitness and the body. Price related the model to individuals with eating disorders as an example to illustrate this point. Conceptually, the body ideal component is similar to Kolb's definition and emphasises the sociocultural factors that influence the perception of BI. Similarly, Schilder<sup>3</sup> emphasised that BI is a social phenomenon; for example, others' BIs and attitudes influence an individual's BI. In HNC patients, the body ideal changes because of the disease process itself, and as a consequences of both ablative and rehabilitative surgeries, which negatively influence society's perceptions of the altered appearance-11,24 Body presentation is the third component of Price's model, which

represents the presentation of the body to the outside environment and draws attention to the symbolic value of the BI. This is similar to Schilder's libidinous structure of BI, as he argued that individuals change their BI by masking it with clothing. Similarly, people with an altered facial appearance due to HNC attempt to conceal or camouflage their appearance with clothing or sunglasses<sup>19</sup>, though this is difficult due to the high visibility of the face.<sup>25,2</sup>

Although Price's model has been well received among the nursing community<sup>27</sup>, one limitation is that it does not acknowledge the role of physiology or pathophysiology in the development of BI. Price<sup>13</sup> argued that previous models of BI were complex, while his model simplifies the concept and makes it more applicable for nurses who encounter BID patients more often. However, this model does not take into consideration that, although the body reality may be altered, there is also a dysfunctionality associated with the altered BI1,28 and its psychological effects, as Schilder<sup>3</sup> suggested. For example, surgical ablation of the lower jaw results in the inability to eat and communicate, which can possibly erode a person's self-confidence and self-esteem with diminished BI, resulting in manifestations of anxiety and depression. 11,22,28 Dropkin et al. 1 proposed a conceptual framework of coping with disfigurement after HNC surgery, which recognised that HNC has a considerable impact on the physiological, psychological and social attributes of an individual's BI. This framework mirrors Schilder's tri-dimensional construct of BI, but also introduces the notion of BI reintegration, which recognises the necessity of identifying and appreciating the extent of the altered BI to facilitate post-operative strategies that promote the reintegration of BI.

# Physiological and psychosocial significance of BI and the face

The face, head and neck areas are the most prominent and visible parts of the body, and they play a significant role in the BI schema.<sup>2</sup> The face has a dual role, as an organ of both identity and physiology.<sup>29</sup> In addition, Borah and Rankin<sup>30</sup> proposed a ternary role in identity, social interactions and physiological functions wherein the face integrates with the psychological processes. The functionality of the face they suggested is concordant with Schilder's model.

According to a number of authors, the face is the primary organ of an individual's identity and interac-

tions with others, including their representation of BI to the world.<sup>29,31</sup> The face expresses the individual's inner self and personality<sup>32,pg13</sup>, therefore it is an organ of self-expression through verbal and non-verbal cues<sup>29,33</sup> and facilitates social interaction.<sup>34</sup> Communication through non-verbal cues reflects both positive and negative facial expressions, such as pain, deception<sup>35</sup>, unpleasantness, happiness, anger and fear.<sup>33,36</sup>

Physiologically, the face has numerous functions; for example, the eyes are a source of visual perception<sup>31</sup> through which the self and world are experienced.32,pg14 Schilder3 was of the opinion that visual perception has a strong influence on BI. The ears and the nose perceive auditory and olfactory sensory input, respectively. Similarly, Schilder recognised that the ears play an important role in integrating the sensual experiences and construction of BI. The mouth expresses verbal emotions; the voice articulates an individual's intentions, ideas, perceptions, self-reflection and awareness whilst also facilitating mastication. 31,32,pg13 As a sensory organ, the face transmits tactile stimuli perceived through the skin.<sup>29</sup> Schilder appreciated that the sensory organs afforded BI contact with the outside world, thus the face is integral in formulating BI.

In most cultures, the face is a symbol of attraction<sup>37</sup>, as certain values are placed on its 'attractiveness'.<sup>38</sup> Dion et al.<sup>39</sup> observed there are stereotypes associated with the notion that 'What is beautiful is good'. That is, there are positive attributes associated with physical attractiveness. An attractive face has positive attributes that are socially desirable, which leads to better prospects for happy personal and professional lives.<sup>39</sup> Similarly, individuals with HNC express feelings of unattractiveness as a result of surgery and its related to changes to the face.<sup>19,25</sup>

Cash et al.<sup>40</sup> identified the great importance that is placed on appearances and valuing specific body ideals, which they referred to as body-image investment. In their view, people spend most of their lives manipulating the way they look so that they are presented to the world in a positive light.<sup>41</sup> This implies that physical appearance plays an important role in the world's perception of an individual. Furthermore, this perception is dynamic, as people can manipulate how they present themselves from one interaction to the next.<sup>41</sup>

# Physiological and psychosocial implications of BI disturbance in individuals with head and neck cancer

# Definition of body image disturbance

A variety of terms for BID have been suggested. 13,28,42,43,44 For example, Engel and Keizer 45 proposed that BID is the disturbance in the visual aspects of the mental body representation. However, this definition is rather limited, as it does not take into consideration the functional and psychosocial factors that influence BI. According to Rhoten 46, the three defining attributes of BID in adults treated with cancer are self-perception of a change to appearance and displeasure with the change or perceived changes in appearance, a decline in the area of function and psychological distress regarding changes in appearance and/or function. Rhoten's definition correlates well with Schilder's BI conceptual framework.

# Body image disturbance in individuals with head and neck cancer

Due to the close proximity of the vital structures in a small anatomic area, ablative surgery in the head and neck area is often radical<sup>9</sup>, causing significant disfigurement and BID.<sup>19,47</sup> BID results in profound trauma for the individuals and continues to do so well after completion of the treatment.<sup>48,49</sup> Existing data suggests that the prevalence of BID in HNC patients ranges from 75–77%<sup>10</sup>, with disfigurement and dysfunctionality being the main attributes of BID.<sup>50</sup>

'Disfigurement' refers to the surgical removal of bony and/or soft tissues such that normal facial contour is permanently altered.9 Disfigurement can potentially bring permanent changes to a person's self-image, as endorsed by changes in physical appearance, sexual attractiveness and self-esteem. 42,50 The altered selfimage then affects their presentation of the self to the world<sup>42</sup>, thus patients have a diminished sense of self.11 'Dysfunction' denotes the associated sensorimotor deficit(s) that may occur as a result of the removal of vital structures.9 Dysfunction in HNC patients manifests as impaired verbal articulation and aphonia, which lessens the ability to communicate; reduced masticatory function; and a loss of vision, smell, hearing and/or taste. 19,28 Schilder 3 suggested that any change in function has an immediate influence on BI, therefore dysfunction can erode selfimage and self-confidence<sup>11</sup>, as the dysfunction is a constant reminder of the disease and lack of normality.<sup>19</sup> Dysfunctionality is also associated with a

diminished sense of existential well-being.<sup>51</sup>

Schilder referred to this change of self as depersonalisation, a change in the self and the outside world.<sup>3,pg137</sup> Depersonalisation is the failure to integrate the changed self and the re-establishment of a new meaning, thus it becomes a source of psychological and emotional impairment/distress. Schilder was of the view that every emotion has the potential to change the BI, as emotional attitudes are inseparable from sensory experiences. Both disfigurement and dysfunction are integral to BI, as a person's physiological experiences also cannot be separated from their psychological and social experiences. Furthermore, BID may be exacerbated by strangers' reactions to the disfigurement or dysfunctionality. 19,51 Hence, in HNC patients, the reactions of others to their changed BI has a profound effect on their quality of life, leading to maladjustment or poor coping strategies, such as behavioural disengagement and social isolation. 10,21,22 Schilder asserted that the 'BI is a social phenomenon'.3,pg217

Lang et al.<sup>11</sup> conducted a systematic review and a meta-synthesis of 29 qualitative studies aimed at broadening the understanding of the psychological experiences of patients living with HNC. Themes that emerged included: uncertainty and hope, disruption with daily life, the diminished self, making sense of the experience, sharing the burden and finding a path to move forward with life. Generally, there was a sense that patients moved between hope and despair and struggled with disruptions to their daily lives and the uncertainty of the future caused by their cancer and its treatment. The disruption of daily life consequent to disfigurement and dysfunction was experienced in all aspects of life, ranging from mastication and verbal communication to relationships, socialising and self-identity disconnects. These findings support Schilder's<sup>3</sup> view that suffering from any organic disease will bring about a change in self-perception and libidinous structure. Schilder also appreciated that depersonalisation can be a source of psychological impairment.

Bjordal et al.<sup>8</sup> investigated the health-related quality of life (HRQL) of 357 HNC patients before, during and after cancer treatment. The European Organisation for Research and Treatment of Cancer and head and neck-specific questionnaires (QLQ-H&N 35) were used to assess HRQL at baseline, and after 1, 2, 3, 6 and 12 months. With a survival rate of 78%, only

218 (61%) of the participants had a complete followup during the different assessment phases through 12 months. The global assessment of the HRQL showed a deterioration in the first two months during treatment, but a return to baseline levels at 12 months' follow-up. However, the authors identified variables from the QLQ-H&N 35 that also had significantly poorer outcomes, such as swallowing, social eating, speech, pain, xerostomia and emotional functioning, none of which had improved at the 12-month followup, suggesting the long-term effects of BID. Consistent with these findings, Fingeret et al.<sup>28</sup> observed lower quality of life (QOL) scores in the emotional and functional domains, reflecting poor QOL outcomes related to dysfunctionality. The findings underpin Schilder's observations that physiological function is an attribute of BI, which in turn influences social function and affirms the importance of providing support in order to enhance BI reintegration.<sup>2</sup>

#### **CONCLUSION**

BI is a dynamic, multidimensional construct that encompasses the perception of an individual's physical appearance, function and the emotions associated with this perception.<sup>2</sup> The face, as the site of various organs, is fundamental in the formulation and development of BI. Through its varying functions, the face integrates the self with the environment and the body's psychological processes.<sup>3</sup> HNC patients experience significant disfigurement and dysfunctionality consequent to HNC treatment<sup>10</sup>, with concomitant BID.<sup>11</sup> An extensive set of literature has highlighted that disfigurement and dysfunctionality in individuals with HNC46 are sources of psychological distress11 and contribute to poor QOL.8 Hence, BI theories are valuable frameworks for understanding BI and BID in this group of individuals.

Kolb's model emphasises the importance of the relationship between the somatosensory perception of the body and the cognitive—behavioural responses mediated by the ego (personality); therefore, BID occurs in this context. Price<sup>13</sup>, by contrast, argues that a satisfactory BI is manifest when the three domains of BI (body reality, body ideal and body presentation) are in equilibrium. The limitation of both of these models is their lack of consideration for the dysfunctionality commonly found in HNC patients and the concomitant psychosocial distress.

Schilder appreciates the complexities of BI and that it is not the mere 'picture of our own body which we form in our minds'.<sup>3, pg11</sup> His framework embodies BI and allows for an integrated and inclusive approach to BI in individuals with HNC. This framework may be integrated into comprehensive care for HNC to identify patients at risk, and to assess and proactively address potential BID related to visible bodily changes (disfigurement), dysfunction (e.g., impaired verbal articulation, loss of vision, reduced masticatory function) and adverse psychosocial outcomes (e.g., anxiety, depression). Thus, his conceptual framework of BI remains contemporaneous with the current views of BI and current research lines, as evidenced by the recognition of function/dysfunction as an important aspect of BI<sup>18</sup> and the proposal for an integrated biopsychosociocultural framework.<sup>20</sup>

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#### **KEY MESSAGES**

- Body image theories are important for elucidating body image disturbances in individuals with head and neck cancer. According to Schilder's tridimensional construct, the face is integral in the formulation and development of body image.
- The aim of the paper is to appraise Schilder's body image conceptual framework with emphasis on the face as an integral organ in formulating body image.
- As a tri-dimensional construct, Schilder explored the physiological basis of body image, including its libidinous structure and sociological aspects. Thus, within this construct and in relation to the face, the defining attributes of body image disturbance are self-perceived changes to appearance and displeasure with these change, the decline in the area of function and psychological distress regarding changes and/or function.
- In short, Schilder uses an integrated approach to appreciate the complexities of body image and body image disturbances.

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