The Experience of Acquiring a Significant Change to Facial Appearance

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Declaration

This work has not been submitted to any other institution, or for the purpose of obtaining any other qualification.

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Abstract

This thesis was concerned with the psychosocial experience of living with a significant change to facial appearance acquired through trauma or disease. The thesis comprises a literature review and a report of an original research study. The review used a meta-ethnography approach to synthesise qualitative literature on the experience of altered facial appearance following cancer. The findings demonstrate the varying experience of changed facial appearance depending on the stage of the disease or treatment, with appearance being more salient at less acute stages of cancer treatment. Changes to appearance lead to experiences of stigma and threatened self-image and self-identity, necessitating a range of coping strategies. Clinical implications and future research needs are outlined. The research study aimed to understand the experience of living with a facial prosthesis using Interpretative Phenomenological Analysis. Findings indicate that a prosthesis could restore normalcy and enable social participation, however the impact of having altered facial appearance continued to pervade the experience and practicalities continued to be problematic. Social support and humour were notable factors contributing to positive adjustment. This research implicates a role for peer support interventions in this population, and further research is needed to explore different stages and levels of adjustment.

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“Give thanks to the LORD, for he is good; his love endures forever.”

Contents

Section 1

Literature Review

Cancer and changes in facial appearance: a meta-ethnography of qualitative studies

Abstract

Objectives: This review aimed to understand the experience of changed facial appearance as a result of cancer by synthesising the findings of qualitative studies.

Methods: Noblit and Hare's meta-ethnography approach was used. A search of four databases using terms relating to qualitative research, cancer and changed facial appearance identified 13 papers. Findings of all papers were synthesised to elicit and interpret themes both from the data and from the original authors' conclusions.

Results: The experience of changed facial appearance after cancer occurred in three contexts. In the context of the disease, subthemes were the primacy of survival, the changing relationship with the disease and the impact of the care team on the experience of changed appearance. In the context of the social world, subthemes were positive reactions, negative reactions and coping strategies. In the context of the self, subthemes were the self under attack, self-to-self relating, the self in the world and rebuilding the self.

Conclusions: Models of felt and enacted stigma are supported. In addition, cancer and changed facial appearance interact in their contributions to overall experience. The experience of appearance change is tempered by the illness, and the experience of having had cancer can be kept alive by the changed appearance.

Practitioner points:

- Clinicians should facilitate open, person-centred opportunities for patients to discuss the impact of changed appearance on their overall recovery.
- Peer support for people whose facial appearance has been altered by cancer is crucial; this may be formally or informally organised.

Introduction

Changes to facial appearance as a result of cancer and cancer treatments have a significant impact on psychosocial adjustment. Head and neck cancer (HNC) covers a range of cancers affecting the head and neck including oral, nasal and orbital areas. HNC has the seventh highest mortality rate of all cancers and there are around 600,000 new cases of HNC worldwide each year (Boyle & Levin, 2008). The symptoms of HNC can alter appearance, for example through neoplastic growth, however resecting surgical treatments are the principal cause of sometimes extreme changes to appearance (Rumsey & Harcourt, 2005). HNC does not normally include skin cancers; however, skin cancer is often treated with resecting surgery that can change facial appearance in a similar way to HNC. Surgery around the neck can also result in constricted lymphatic flow in the face, leading to temporarily altered facial appearance as a result of lymphoedema. Reconstructive surgery once the cancer has been removed can help restore appearance to a large degree but patients are often left with some level of long term change to their appearance.

Adjustment to altered facial appearance following cancer varies considerably, suggesting a complex interaction of risk and protective factors (Clarke, Newell, Thompson, Harcourt, & Lindenmeyer, 2014). Some studies have identified positive adjustment in this population (e.g. Katz, Irish, Devins, Rodin, & Gullane, 2003; Vickery, Latchford, Hewison, Bellew, & Feber, 2003) demonstrated by measures of quality of life, depression and anxiety. Conversely, other quantitative studies report elevated levels of depression, social anxiety, poor body-image and shame (Fingeret et al., 2012; Neilson et al., 2013; Clarke et al., 2014). Several studies indicate that women and those with low social support are most at risk of psychological distress (Katz et al., 2003; Bowers, 2008; Caddick, Green, Stephenson, & Spyrou, 2012). These equivocal findings may be a result of the wide range of measures and methodologies employed. Qualitative research may benefit the field through in-depth exploration of experience to develop theories that may warrant further quantitative investigation.

Although objective levels of adjustment and quality of life in cancer patients with altered facial appearance are well documented, the phenomenological experience of managing the specific dual challenges of cancer and altered facial appearance is less clearly understood. Lang et al.'s (2013) meta-synthesis of 29 qualitative studies representing 345 participants explored the experience of living with HNC and identified six core themes; uncertainty and waiting, disruption to daily life, the diminished self, making sense of the experience, sharing the burden, and finding a path. The impact of altered appearance was relevant in several of these themes; however, the focus of the review was on the wider experience of HNC with many of the papers addressing issues such as communication, eating and health promotion. The psychosocial experience of living with altered appearance throughout the cancer journey would therefore benefit from more targeted exploration to understand how changes to appearance may interact with cancer. Some qualitative studies have sought to fill this gap in the literature by focusing specifically on the experience of changed appearance after cancer; however, these small studies are limited in scope and transferability. A meta-ethnographic design has been employed by this review, which seeks to bring together and synthesise the findings of qualitative studies in order to add to the theoretical understanding of the experience of altered facial appearance after cancer.

Throughout this review, the term "changed facial appearance", or similar, has been used as a neutral label to encompass the meaning of terms commonly used in the literature, for example, "disfigurement", "mutilation" or "defect".

Methods

This review was driven by a review protocol and was conducted in three stages. First, a systematic search of qualitative studies looking at aspects of changed facial appearance as a result of cancer. Second, a quality appraisal of the studies identified by the search. Third, synthesis of the findings using Noblit and Hare's (1988) meta-ethnography approach.

Systematic search

No previous review of qualitative research on this subject was identified by a search of the Cochrane Library. Lang et al.'s (2013) review explored the overall experience of HNC, but was not focused on changes to facial appearance; for the purpose of this meta-ethnography, papers were included if they specifically aimed to explore some aspect of the experience of changed facial appearance.

Cooke, Smith, and Booth's (2012) Sample, Phenomenon of Interest, Design, Evaluation, Research type (SPIDER) tool was used to determine the key elements of the review, as outlined in Table 1.

Table 1

Key elements of search identified with the SPIDER tool

Study components	Key elements
Sample	People with current or previous cancer affecting the face (e.g., HNC, skin cancers)
Phenomenon of Interest	Experience of changed facial appearance
Design	Interviews, focus groups, case studies
Evaluation	Psychological and psychosocial experience, phenomenology
Research type	Qualitative, mixed methods

A search was conducted on four electronic databases at all time points; Web of Science, CINAHL, PsycInfo and Scopus. Citation and ancestry searches were conducted on all relevant papers, which yielded several additional papers. Search terms were identified using the SPIDER tool alongside key words noted in the literature (e.g. Lang et al., 2013; Rhoten, Murphy, & Ridner, 2013; Fingeret, Teo, & Goettsch, 2015); synonyms and variations in terminology were included. The complete list of search terms is documented in Appendix A.

In the first instance, titles and abstracts of all articles were screened to assess relevance to the review question according to the inclusion and exclusion criteria in Table 2. The full texts of the remaining papers were subsequently screened in the same way. Duplicate articles were removed at this stage. Figure 1 illustrates the selection process.

Table 2

Inclusion and exclusion criteria

Inclusion	Exclusion
Qualitative studies taking a 'Big Q' approach (i.e. reflexive analysis of rich data; Kidder & Fine, 1987)	Qualitative studies taking a 'little q' approach (i.e. qualitative data collection without reflexive analysis; Kidder & Fine, 1987)
Subjects: Individuals with a past or present diagnosis of cancer affecting the head, neck or face	Not relating to cancer Focus only on family or carer perspectives
Phenomenon of Interest: the experience of changed facial appearance resulting from cancer	Not relating to experience of changed facial appearance Studies of non-facial appearance
Peer-reviewed journal study article	Not in English

A total of 13 articles, representing 12 studies, met the inclusion criteria. Two articles reported different aspects of the same study (Bonanno & Choi, 2010; Bonanno & Esmaeli, 2012). All papers were published from 1994-2016 and covered different aspects of the experience of individuals with changed facial appearance as a result of HNC, facial skin cancers and cancer-related resecting surgery. Participants in the studies were 58% female (n=118) and covered a wide range of ages (16-84 years). All studies used line by line coding of qualitative data to elucidate themes from the data. A range of methodological approaches were employed including grounded theory (GT), interpretative phenomenological analysis (IPA) and other phenomenological approaches. A recognised methodological approach was not specified in three studies.

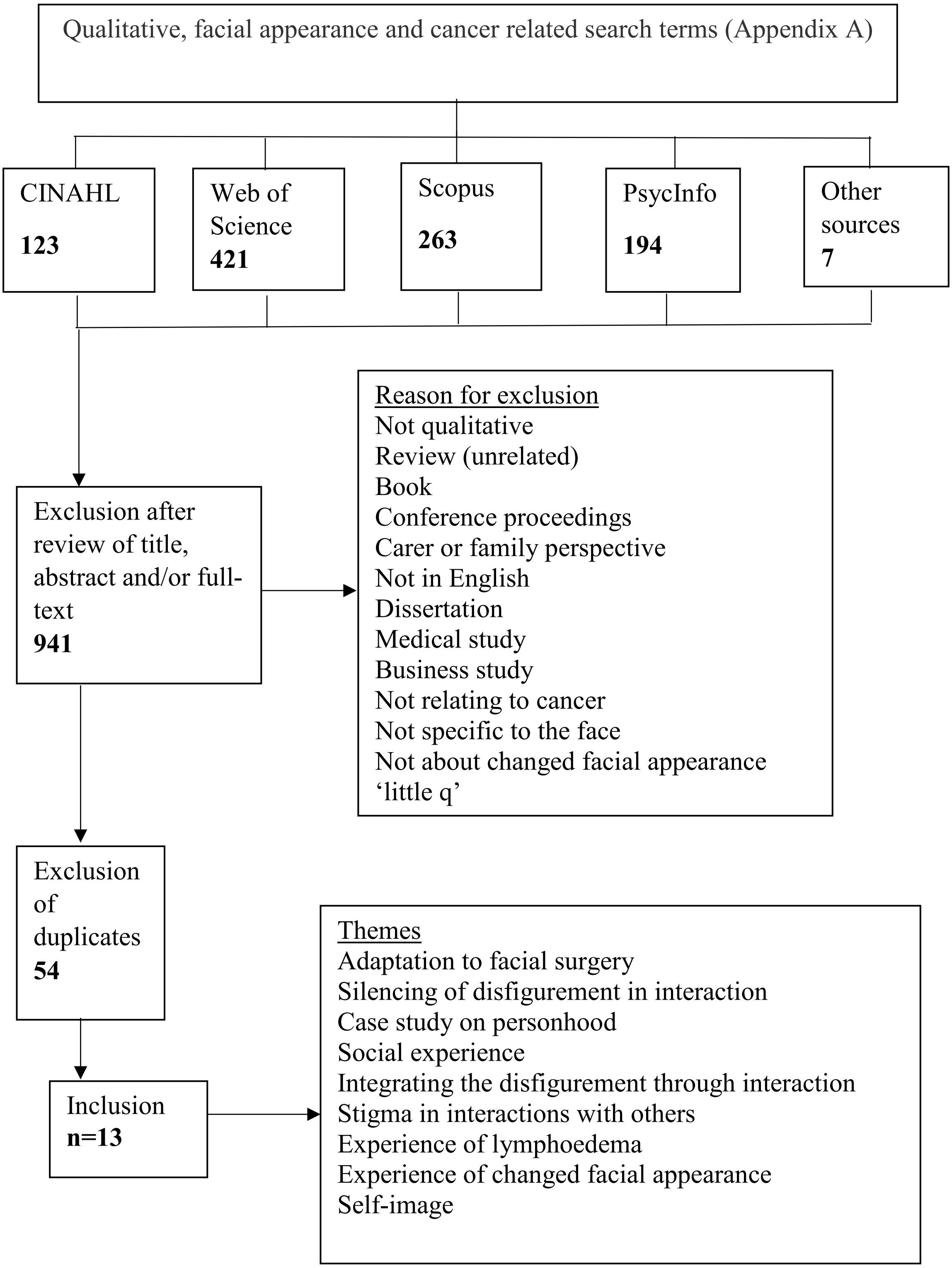

Figure 1. Process of selecting papers for inclusion

Quality Appraisal

All studies were appraised for quality using a tool (Appendix B) based on the Critical Appraisal Skills Programme Checklist for Qualitative Research (CASP, 2013) and the quality framework for qualitative evaluation developed by the National Centre for Social Research (2003). These modified tools have been used in previous meta-ethnography studies (e.g. Campbell et al., 2003; Malpass et al., 2009). The overall level of quality of each paper was classified according to Dixon-Woods et al.'s (2007) categories outlined in Table 3.

All studies were appraised for quality by the researcher, and 20% (n=3) were selected at random and appraised by a research supervisor. Discrepancies in the appraisal were noted for one item in two of the studies and agreement was reached through discussion (Appendix C). All papers were included in the meta-ethnography to encompass the full range of potential themes; however, quality concerns are discussed alongside the results to determine the contributions of each paper and to clarify the methodological issues evident in the field. Table 4 summarises the papers included in this review.

Table 3

Classifications of quality appraisal

Category	Abbreviation	Definition
Key Paper	KP	Methodologically sound and highly relevant.
Satisfactory	SAT	Methodologically sound
Questionable	Q	Some methodological issues, included in review but interpreted with caution
Fatal Flaw	FF	Fatal flaw in methodology, included in review but with significant caution

Table 4

Summary of details and main themes of selected studies

	Author (year)	Setting and country	Participants	Aim	Design	Analysis method	Key themes	Quality appraisal
1	Van Doorne, van Waas, and Bergsma (1994)	Outpatient and community, The Netherlands	HNC patients with changed facial appearance, n=24. Male=19, female=5. Average age 65.	Explore coping in cancer patients with changed facial appearance	Reflective, semi-structured individual interviews	Unspecified	Fear of dying, appearance changes as the price for survival, coping	Q
2	Furness, Garrud, Faulder, and Swift (2006)	Community and outpatient, UK	Facial surgery patients n=29 (cancer patients n=21). 65% female, 35% male. Age 34-84.	Explore and explain the experience of adapting to facial surgery	Semi-structured focus group; individual interviews	GT	Demands, resources, responding and managing, and consequences of facial surgery	SAT
3	Konradsen, Kirkevold, and Zoffman (2009)	Inpatient, Denmark	Facial cancer surgery patients. n=14. Female=5, male=9. Age 25-78.	Explore and explain changed facial appearance and nurse-patient interactions following cancer surgery	Semi-structured interviews, everyday nurse-patient interactions	GT	Minimizing appearance, appearance is a luxurious problem and another time, another place	KP

	Author (year)	Setting and country	Participants	Aim	Design	Analysis method	Key themes	Quality appraisal
4	Speraw (2009)	Community, USA	1 female with multiple facial cancer treatments, age 16.	Explore the concept of personhood in a case study	Semi-structured individual interview	Thomas & Pollio's (2002) phenomenological approach	Personhood and agency in health care	SAT
5	Turpin, Dallos, Owen, and Thomas (2009)	Outpatient, UK	HNC surgery patients with altered appearance, n=10. Male=6, female=4. Age 41-66.	Explore the personal meaning and impact of HNC, in particular the individual's sense of self	Semi-structured interviews and Repertory Grids	IPA	Destruction of self, altered relations to body, disenfranchised self and conservation of self	KP
6	Bonanno and Choi (2010)	Cancer hospital, USA	HNC surgery patients, n=14. Male=8, female=6. Age 31-81.	Analyse patterns of social interaction as experienced by people with changed facial appearance after cancer	Semi-structured phone interviews with individuals and family members	GT	Intrusion, sympathy and benign neglect in social interactions for individuals who are always or only occasionally comfortable	Q

	Author (year)	Setting and country	Participants	Aim	Design	Analysis method	Key themes	Quality appraisal
7	Konradsen, Kirkevold, McCallin, Caye-Thomasen, and Zoffman (2012)	Community and outpatient, Denmark	Facial cancer surgery patients, n=12, Female=6, male=6. Age unspecified.	Understand the ongoing process of adjustment to changed facial appearance	Semi-structured individual interviews	GT	Interactional integration of changed appearance facilitates the progression of adjustment	SAT
8	Bonano and Esmaeli (2012)	Cancer hospital, USA	HNC surgery patients, n=14. Male=8, female=6. Age 31-81.	Analyse patterns of social interaction for people with changed appearance after HNC	Semi-structured interviews with individuals and family	GT	Intrusion, sympathy and benign neglect in social interactions in large or small groups	SAT
9	McGarvey, Osmotherly, Hoffman, and Chiarelli (2014)	Outpatient, UK	HNC patients with lymphoedema, n=10. 80% male, 20% female. Age 32-75.	Explore how lymphoedema following HNC treatment affects patients	Semi-structured individual interviews	Unspecified	Negative psychosocial sequelae of lymphoedema, coping strategies	SAT

	Author (year)	Setting and country	Participants	Aim	Design	Analysis method	Key themes	Quality appraisal
10	Costa, Nogueira, Lima, Mendonca, and Leles (2014)	Inpatient and outpatient, Brazil	Facial cancer surgery patients, n=10. Male=5, female=5. Age 26-72.	Explore experience of changed facial appearance after HNC surgery	Semi-structured individual interviews	GT	Discovering cancer, coping with cancer and appearance, reconstructing a new identity	SAT
11	Henry et al. (2014)	Outpatient, Canada	HNC surgery patients with changed facial appearance, n=14. Male=7, female=7. Age 39-79.	Explore the lived experience of changed facial appearance in the course of HNC.	Semi-structured individual interviews	IPA	Oscillations between ruptured self-image and normalcy and acceptance	KP
12	Nayak, Pai, and George (2016)	Tertiary care, India	7 female HNC patients. Age unspecified.	Understand self-image in HNC patients	Semi-structured individual interviews	Colaizzi’s (1978) approach	Valuing the internal above the external self	FF
13	Lee, Klassen, Lawson, Cano, Scott, and Pusic (2016)	Cancer hospital, USA	Facial skin cancer surgery patients, n=15. Male=6, female=9. 3 aged 20-40, 5 aged 40-60, 7 aged 60-80.	Identify aesthetic and health issues of facial cancer surgery patients.	Semi-structured individual interviews	Unspecified; line by line coding and constant comparison	Appearance-related, psychological, social and physical concerns, and satisfaction with care	SAT

Synthesis of studies

Meta-ethnography is the interpretative, rather than integrative, synthesis of qualitative data (Harper & Thompson, 2011) and aims to identify new themes from the data. Accordingly, papers in the present review were synthesised based on their first, second and third order constructs (Table 5) over four phases as used by Malpass et al. (2009). The process of analysis was audited by the research supervisor for 20% of the papers (n=3).

Table 5.

First, second and third order constructs

First order construct	*Interpretations of experience:* the participant's account of having changed facial appearance as a result of cancer
Second order constructs	*Interpretations of interpretations of experience:* the themes developed by the original authors
Third order constructs	*Interpretations of interpretations of interpretations of experience:* the new concepts and themes developed in the process of synthesis

Phase 1.

All papers were read and reread in chronological order, noting the second order constructs identified by the original authors and patterns in themes across studies.

Phase 2.

A table of second order constructs (Appendix D) was created with reference to raw data in the original papers (first order constructs). Conceptual maps were drawn (Appendix E) linking the second order constructs in each paper, in order to maintain the contextual meaning of each study.

Phase 3.

Constructs from each study were translated into each other by comparing the themes across studies. Second order constructs were analysed for latent meaning and this was noted. However, new concepts were not developed at this stage.

Phase 4.

Third order constructs were generated based on the analysis described in phase 3. Noblit and Hare's (1988) method of generating 'lines of argument' was used here to build the synthesis, as the selected studies explore different aspects of the phenomenon of changed facial appearance after cancer and the meta-ethnography aims to develop a fuller picture by considering the studies as a whole. To achieve this, translated constructs were grouped into new conceptual contexts.

Results

The synthesis process identified 10 interpretative third order constructs synthesised from 45 second order constructs (Table 6). Third order constructs could be grouped into three conceptual categories based on the contexts in which participants described their experience of changed facial appearance. First, the context of the disease: this included the primary importance of survival which puts appearance into perspective, the relationship with the disease and the disease's impact on experiences of appearance over the course of the cancer journey, and experiences with the care team. Second, the context of the social world: this included positive and negative reactions, and the strategies used to cope with these. Third, the context of the self: this included the attack to the self resulting from the changed appearance, self-to-self relating, the self in the world and rebuilding a sense of self. These themes are illustrated with raw data from participants as included in the original papers, in the form of italicised quotes.

Table 6

Themes supported by each article in the meta-ethnography

	Context of disease			Context of social world			Context of self			
Author (year)	Survival is paramount	Relationship with disease	The care team	Positive reactions	Negative reactions	Coping strategies	Self under attack	Self-to-self relating	The self in the world	Rebuilding the self
Van Doorne et al.(1994)	X	X		X	X		X			X
Furness et al. (2006)	X				X	X	X			X
Konradsen et al. (2009)	X	X	X		X					
Speraw (2009)			X		X	X		X		X
Turpin et al. (2009)	X			X	X	X	X	X	X	X
Bonanno and Choi (2010)				X	X	X			X	
Konradsen et al. (2012)			X		X	X		X	X	
Bonanno and Esmaeli (2012)				X	X	X			X	
McGarvey et al. (2014)						X	X	X		
Costa et al. (2014)	X	X			X	X		X		X
Henry et al. (2014)	X	X	X	X	X	X	X	X	X	X
Nayak et al. (2016)	X					X				X
Lee et al. (2016)	X	X	X			X	X			

1. The context of the disease

Several third order constructs related to participants' experiences of their changed facial appearance in the context of the disease. These often linked with the early stages of cancer and treatment; including the preoperative changes in appearance as symptoms became more apparent, and the postoperative period when the extent of changed facial appearance is first evident after surgery.

1.1 Survival is paramount

A recurring theme in many papers (Van Doorne et al., 1994; Furness et al., 2006; Konradsen et al., 2009; Turpin et al., 2009; Costa et al., 2014; Henry et al., 2014; Lee et al., 2016; Nayak et al., 2016) was the importance placed on surviving the cancer, and how this influenced experiences of appearance. Large changes to facial appearance were reported as a secondary issue compared with surviving the disease, and a necessary "trade-off" or price that needed to be paid to continue living:

> *"I actually don't give a toss what I look like because I'm alive, and I just think the issue of cancer returning and doing its worst, it's a far bigger issue than how you look" (Furness et al., 2006)*

Konradsen et al. (2009) found that Danish participants' experience of appearance as a luxury issue stemmed from interactions with nursing staff in the postoperative period. Participants experienced a "silencing" of their changed appearance in that body image was not discussed. In these early days after surgery, participants felt that they were lucky to be alive, and therefore should not complain about their appearance which represented the price paid for survival:

> *"So I feel that it's kind of a luxury problem, and nothing to bother anyone with, the fact that I feel sad about looking this way. I imagine there's probably someone out there in more need"* (Konradsen et al., 2009).

Costa et al.'s (2014) GT study with Brazilian participants found that they accepted their facial appearance as the "price" for removing the threat of cancer, and that changed facial appearance was part of the destiny or divine purpose for their lives. A study with Indian participants also found views that demoted the significance of appearance compared to health, with one participant saying:

> *"What do I have with beauty? If God gives good health, that's enough."* (Nayak et al., 2016).

These studies suggest a cultural and spiritual aspect of the experience of changed facial appearance after cancer; although appearance concerns were still apparent, the importance of health and survival was given greater worth relative to appearance and a belief in a higher purpose was part of the adjustment process.

1.2 Relationship with the disease

Participants' relationships with the cancer and treatments varied over time and impacted on how the resultant changes to appearance were experienced. Most studies described an emotional journey from concern or denial when symptoms started, shock at the diagnosis, fear about the operation, visceral disgust reactions to postoperative facial appearance, relief that the threat of cancer has been dealt with and worry about recurrence of the disease;

> *"The first moment it really stunned me. The first moment is that shock…and you feel like: how can I live with this?"* (Costa et al., 2014)

Changes in facial appearance took a different level of significance depending on the stage of the disease. Stages of intense worry about the disease were characterised by a fear of dying – at these times the prospect of changed facial appearance seemed of less significance, or was not considered at all. However, once the cancer was successfully removed and the threat of dying was no longer at the forefront, participants were then faced with the task of living with a changed face, which consequently took on greater significance (Furness et al., 2006). Later, when the physical wounds of the surgery had healed, changed facial appearance could act as an ever-present reminder of the cancer, perpetuating feelings of worry about recurrence. Thus the fear of dying was, for some, kept alive by continuing to check for changes in facial appearance (Henry et al., 2014):

> *"…I started looking to see if it was a bit red. And then you start wondering, 'OK, so this is how the first one started….is this a sign, you know?"* (Henry et al., 2014)

Social and practical problems meant that participants were constantly aware of their appearance and thus were constantly reminded of the disease. The curiosity and sometimes stigmatizing reactions of others drew participants' attention back to the distressing narrative cancer:

> *"They're talking about your neck, your scars. You hear different things… And part of you just feels like turning around and saying, 'It's cancer!'"* (Henry et al., 2014)

Facial appearance was also inextricably bound up with practical problems (Lee et al., 2016), such as functional difficulties with eating or speaking, the need to clean the site, and sometimes the use of prostheses. Participants engaged in more health-seeking behaviours, for example reducing sun exposure, and they encouraged others to do the same:

> *"This nose thing has changed my whole perspective. I now wear hats. I have sun block in my car."* (Lee et al., 2016)

1.3 The care team

During the diagnosis and treatment period, the way in which the care team dealt with the changed facial appearance was important for participants (Konradsen et al., 2009; Speraw, 2009; Henry et al., 2014; Lee et al., 2016). Positive and negative characteristics of care teams were identified. Henry et al. (2014) reported that professionals who took an empathic, person-centred, and open approach facilitated better adjustment to changed facial appearance;

> *"The backup from the nursing staff is instrumental in making people happy" (*Lee et al., 2016*)*

> *"It's so personalised that already it takes away the fear … in moments like these, that's what you need the most – that little extra human touch"* (Henry et al., 2014).

Participants' descriptions suggest a balance is needed between acknowledging appearance changes without stigmatizing. Konradsen et al. (2009) found that appearance was minimised by the care team, meaning that the participant's negative feelings about their appearance were silenced as they learned that altered appearance, while an important issue to them, was not something that was discussed with nursing staff. Konradsen et al. (2012) extended the study and found that psychological integration of changed appearance only began once this silence was broken in interactions; in this study integration only happened after the participant had left hospital. Speraw's (2009) case study of a teenage girl with multiple cancers of the face found that she experienced considerable stigmatization by healthcare professionals:

> *"Just because my eyes are plastic and my ears are rubber doesn't mean I shouldn't be talked to like anyone else…I have the nurses yell at me 'cos they act like I can't hear at all. Shouldn't they know better?"* (Speraw, 2009)

Nurses made incorrect assumptions about her abilities based on their reaction to her appearance. Her experience suggests that her appearance prevented professionals from observing clinically relevant information, possibly because her appearance was preoccupying or because a disgust reaction prevented staff from giving their full attention. In some ways, altered facial appearance resulted in this participant being seen as less human by even experienced healthcare professionals.

2. The context of the social world

A number of third order constructs emerged relating to participants' experiences of their altered facial appearance within a social context. These included the positive and negative reactions elicited by others and the coping strategies employed by participants to manage in the social world.

2.1 Others’ positive reactions

As noted above, positive interactions with professionals during the treatment phase included empathic listening and explaining; these helped participants to feel safe and accepted (Henry et al., 2014). Beyond the hospital environment, participants described how explicit commenting on facial appearance, initiated by other people, could help them to feel “normal” and enable them to begin integrating the changed appearance into a new self-construct (Konradsen et al., 2012). Having permission from others to have a forthright conversation about appearance could reduce the sense of “otherness” by assuaging curiosity and concern which could otherwise engender stigmatization:

> *“I went to my daughter’s school and told her classmates what had happened… Many children and their parents came up to me and asked … ‘why is your face swollen? Did anything happen to you?’ and so on. So from that day on, everything became normal.”* (Konradsen et al., 2012)

On the other hand, sometimes the experience was more positive when appearance was not acknowledged at all. One study (Bonanno & Choi, 2010; Bonanno & Esmaeli, 2012) focused on social interactions in different types of group, and found that stigma was not perceived when strangers or acquaintances behaved with a “benign neglect” towards appearance. In group settings, when appearance was paid no special attention, participants felt “normal” and enabled to be part of the group as they would have done before the cancer:

> *“They just come and talk to me like I was totally normal…. when people treat you as you are totally normal, and I feel that way, it makes you feel good”* (Bonanno & Esmaeli, 2012)

The size of a social group also helped determine how a response was perceived, for example sympathy and pity was more likely to be experienced as supportive when expressed in smaller groups (Bonanno & Choi, 2010).

In close relationships, comfort, support and acceptance of changed appearance were highly valued across several studies as they enabled participants to talk about their appearance (Van Doorne et al., 1994; Furness et al., 2006):

> *"We talk about it, and it calms me down"* (A participant and her husband; Furness et al., 2006)

These interactions gave validation to participants' concerns and reassurance that valued relationships would not be damaged by the changes in their appearance, and gave them confidence that they could face the future in the context of these supportive relationships:

> *"…the people who I most admire – my husband and my family – were supporting me…and I said, 'these are the main things…then I will tackle the rest!'"* (Costa et al., 2014).

Consistency and predictability in others' reactions was a positive feature. When participants could predict how someone would react to their appearance, they felt more comfortable and confident in social interactions. However, unpredictable responses led to increased anxiety and uncertainty. For example, van Doorne et al. (1994) found that encountering partially-known acquaintances presented a particular problem as the participant could not predict if someone would react positively or negatively. Complete strangers and close relations, however, tended to give consistent, albeit different, responses which reduced participants' anxiety by enabling a degree of preparation.

2.2 Others' negative reactions

Negative reactions from others in response to changed facial appearance was a significant theme in the majority of studies (Van Doorne et al., 1994; Speraw, 2009; Costa et al., 2014; Henry et al., 2014; Bonanno & Choi, 2010; Bonanno & Esmaeli, 2012; Turpin et al., 2009; Konradsen et al., 2012). Negative reactions included those of commission (for example, intrusive questions or insults) and those of omission (for example, awkward silences or being avoided). As noted above, negative reactions could first be experienced from nursing staff while still in the hospital setting.

The most frequent negative reaction reported was an incongruent silence. Unusual silence in response to changed facial appearance was perceived as rejection, especially when from a close family member or friend. Some participants tried to talk about their appearance in close relationships but were met with silence and awkwardness which reinforced feelings of isolation (Furness et al., 2006). Many participants described feeling like their appearance would make others uncomfortable, and had a sense of responsibility for not putting others out by exposing them to their changed faces (Turpin et al., 2009):

> *"Sometimes when you meet people, they are afraid to say anything because they are afraid of hurting you…that is a bit sad"* (*Konradsen et al., 2012*)

Participants experienced provoking pity, sadness and sympathy in others (Costa et al., 2014; Henry et al., 2014). Sometimes this was overbearing and out of proportion to participants' perception of the severity of their changed appearance. This increased feelings of being inferior and different to others:

> *"People treat me differently…they are sympathetic, overtly so… this is a person with a visual problem, we'll treat him differently and they do … I think they feel sorry for me"* (Bonanno & Choi, 2010)

Similarly, participants' facial appearance prompted reactions of shock and disgust (Costa et al., 2014; Henry et al., 2014). People would stare, make comments and ask questions. Bonanno and Choi (2010) describe how this felt intrusive, and ranged from outright rudeness ("they run around in front of me and go, 'she doesn't have an eye! Look, look!'"), to subtle looks ("some of the mothers were looking at me strangely…curious, like there's something strange about that woman"). Such responses from others made participants uncomfortable and put pressure on them to share their personal stories with relative strangers, reinforcing feelings of being "abnormal".

Sometimes participants reported being avoided by others. Sexual and intimate relationships became more difficult, with some participants experiencing outright rejection from those closest to them as a result of their changed facial appearance. This rejection by someone so important clearly posed a major threat to some participants' self-esteem:

> *"He's left me. He couldn't cope with the way the disease had affected me … Now I have to go out and find a new boyfriend. That's almost impossible with one eye."* (Konradsen et al., 2012)

The above quote also demonstrates that the rejection reduced confidence for gaining a relationship in the future.

2.3 Coping strategies

Participants employed various strategies for coping with the demands placed on them by others' reactions. Many papers identified social avoidance as a coping strategy (Konradsen et al., 2012*;* Costa et al., 2014; Henry et al., 2014; McGarvey et al., 2014). Participants expected to feel upset in social situations because of negative reactions, and so they avoided these situations (Konradsen et al., 2012). This could lead to increased social isolation and perpetuated feelings of rejection:

> *"I will stay at home; I hate being the centre of attention"* (*Konradsen et al., 2012*)

Participants described how using concealment and camouflage helped them to appear and feel more "normal", thereby reducing negative reactions (Turpin et al., 2009; Costa et al., 2014; Henry et al., 2014; McGarvey et al., 2014; Lee et al., 2016). Participants used dark glasses, scarves, prostheses, long hair and different postures to reduce the visibility of their facial appearance and limit the opportunities for negative reactions. Several participants described how they would not leave the house without using concealment, suggesting that facial difference can be socially disabling.

3. The context of the self

Changed facial appearance had a significant influence on participants' sense of themselves as individuals. In different papers this concept was referred to as sense of self, self-image, identity and personhood. The experiences of changed facial appearance within the context of the disease and the context of the social world fed into the context of the self, so there is considerable conceptual overlap between themes.

3.1 Self under attack

Participants reported that their concepts of their personal identities were ruptured by changed facial appearance:

> *"I felt that [the facial changes] took away from me, from my personality"* (Henry et al, 2014).

Turpin et al.'s (2009) study focused on the impact of HNC on the sense of self, and found that the treatment phase of the disease marked a discontinuation from the previous self and the beginning of a new self:

> *"You just can't live the same life anymore; really you're not the same person at all"* (Turpin et al, 2009).

Facial changes represented a loss of unique, self-defining characteristics. The face had represented an essential part of an individual's construction of themselves and changes to the face caused a rupture in this construction. Participants experienced the loss of valued social and occupational roles as a result of the disease and the changed facial appearance, which was a further attack on the self as unique and valued.

3.2 Self-to-self relating

Across many studies, participants reported negative body image as a result of changes to facial appearance (Turpin et al., 2009; Costa et al., 2014; Henry et al., 2014; McGarvey et al., 2014). They described themselves as ugly, unattractive, undesirable, gross, strange and other derogatory terms:

> *"My general appearance has been altered quite considerably…and all of a sudden to have a big bulbous neck like a cane toad"* (McGarvey et al. 2014).

Numerous participants felt disgusted and repulsed by their appearance and many were reluctant to look at themselves in the mirror. Often participants would refer to themselves as sub-human, using terms like "alien", "not human", "circus beast", and "mutant". For these participants the destruction of the face seemed to correspond with the destruction of what made them human:

> *"Have you seen the film The Fly, well you don't want to …this chap ends up …half man and half fly…and it's not a very nice sight and I tended to feel I was a bit like that"* (Turpin et al, 2009)

Participants felt disenfranchised from themselves; believing that their post-cancer appearance did not match their true identity – the person they saw in the mirror was "not me". Where the pre-cancer face represented the authentic self, the changed face was a diminished, inadequate and false version (Turpin et al, 2009).

3.3 Self in the world

This theme considers the individual's internal perception of themselves around other people. This differs from the external social experience discussed in the context of the social world, although the two are inevitably linked.

Participants were keenly aware of being different from others; of belonging to a separate category because of their appearance. Thus, many participants felt conspicuous around others (Turpin et al., 2009; Bonanno & Choi, 2010; Bonanno & Esmaeli, 2012; Konradsen et al., 2012; Henry et al., 2014):

> *"I feel odd; I feel like people are staring at it"* (Lee et al., 2016).

> *"The look of my face is the elephant in the room" (*McGarvey et al., 2014)

While others' reactions fostered this feeling, participants were inherently aware that their altered appearance would garner unwanted attention:

> *"It's just a bid red square, which almost has a bullseye with arrows pointing to it"* (Henry et al., 2014).

Participants also felt judged by others and inferior compared with society's standards of beauty and "normality" (Van Doorne et al., 1994; Henry et al., 2014).

3.4 Rebuilding the self

An adjustment process in which the sense of self was rebuilt over time was evident (Turpin et al., 2009). This process was gradual and not straightforward; oscillations between old and new identities were common (Van Doorne et al., 1994; Costa et al., 2014; Henry et al., 2014).

While a desire to return to the "old" self was often present, participants also strived to build a new identity in which they took pride in their "survivor" status and could use their experiences for personal development (Costa et al., 2014; Henry et al., 2014). Participants continued to look back to valued aspects of their previous selves, and hoped to continue their rehabilitation towards a better future.

Several factors influenced the process of rebuilding the self. Some participants (Turpin et al., 2009; Lee et al., 2016; Nayak et al., 2016) felt that their older age and later life stage protected them from the potential social implications of having a facial difference:

> *"Not that at the end of the day it really matters, because I'm not a single young man who's likely to be just setting out in life"* (Turpin et al., 2009)

Gender also played a role, with female participants being more concerned with appearance changes (McGarvey et al., 2014) and men being more concerned with functional problems (Henry et al., 2014).

The presence of religious belief could help participants to feel comforted and hopeful about their future with a different facial appearance (Costa et al., 2014):

> *"I went to the church… because if not I think I'd sink into depression and other consequences would come. Then I clung to God too…God has been my support… because if not, I guess I could not bear it"* (Costa et al., 2014).

Personality traits such as optimism and a sense of humour were associated with positive adjustment, while trait anxiety and introversion were problematic (Furness et al., 2006).

Discussion

This meta-ethnography on changed facial appearance after cancer reveals the significant impact of the disease on participants' individual and social experiences.

Findings relating to the general experience of having unusual facial appearance are in line with those previously identified. The emphasis in earlier research tends to be on the negative aspects of the experience, in particular Goffman's (1963) concept of stigma which Scambler and Hopkins (1986) divided into felt and enacted stigma. Felt stigma refers to internalised shame and a fear of rejection or judgement from others; these were encompassed in this review in the contexts of self under attack, self-to-self relating and the self in the world. A loss of identity, loss of roles, negative body image, loss of personhood, self-consciousness and perceived inferiority compared to society's standards of "normal" appearance are aspects of felt stigma found here which have been consistently reported in other research (e.g. Thompson & Kent, 2001; Callahan, 2005). Enacted stigma refers to discriminatory behaviours of others. Enacted stigma was apparent in this review in the negative reactions of others in the context of the social world. For the participants in this review, enacted stigma ranged from awkward silences through to insults and outright rejection in close relationships. Again, these and similar experiences are widely reported in much previous research (e.g. Cooke Macgregor, 1990; Lebel et al., 2013). Stigma has been explained as a result of the potential disruption to social interaction or as linked with an attribution of responsibility to the stigmatized person (Albrecht, Walker & Levy, 1982). Both theories could be relevant to the findings of this review: facial difference is particularly conspicuous in social interaction, and cancer is often linked with lifestyle choices such as smoking and alcohol misuse (Ragin, Modugno, & Gollin, 2007). Kent and Thompson's (2002) model of shame and visible difference fits with the current findings, suggesting that felt and enacted stigma lead to feelings of shame and anxiety, which in turn bring about coping strategies such as concealment, camouflage and avoidance.

Some of the recent research has focused on positive aspects of the adjustment process (Rumsey & Harcourt, 2005), which are corroborated in this review. Egan et al.'s (2011) qualitative study with participants with visible difference found that receiving positive reactions from others, acceptance in close relationships, and seeing the difference as a means of personal growth are central to good adjustment. Many other studies support findings here by indicating that social support is vital to positive adjustment (e.g. Katz et al., 2003; Karnell et al., 2007).

The specific focus in this review revealed the added impact of cancer on the experience of changed facial appearance. The salience of appearance seemed to be particularly sensitive to disease processes. Survival became the paramount priority during the acute treatment phase, and the degree of distress associated with altered appearance increased as the threat posed by cancer decreased. On the other hand, appearance impacted on the experience of cancer. Feelings of shock, fear and worry were kept alive by the changes to facial appearance that acted as an ever-present reminder of the disease. The findings from this review are specific to the experience of changed appearance and therefore extend Lang et al.'s (2013) findings, some of which are also supported by this review. The importance of social support for positive adjustment was significant in both reviews. This review supported Lang et al.'s (2013) theme of "the diminished self" but clarified the significance of appearance concerns as well as functional difficulties in self-identity following HNC.

The findings of this review have implications for clinical practice. Konradsen et al. (2009) found that HNC patients could feel unable to talk about appearance with healthcare professionals because it was seen as a “luxury issue”, and Konradsen et al. (2012) later found that integration of the altered appearance was delayed by this “silencing of disfigurement”. Speraw (2009) presented an account in which enacted stigma was experienced from healthcare professionals, leading to feelings of reduced personhood. Conversely, Henry et al. (2014) found that empathy, openness and a person-centred approach from the care team contributed to positive experiences. Therefore, care teams should acknowledge the potential psychosocial impact of appearance and create opportunities for conversation, whilst being mindful of behaviours which may be perceived as stigmatising. Opportunities for peer support should be provided and recommended to patients, both informally in the hospital setting and subsequently via community or online support groups. Al Gtewi, Owens, and Baker (in press) have found some tentative evidence to support the use of online support groups in this population; further research is required to ratify these findings. These applications could be further informed by qualitative research into positive interactions with healthcare professionals. Some research (e.g. Thambyrajah, Herold, Altman, & Llewellyn, 2010; Llewellyn et al., 2013) already addresses the role of benefit finding and positive adjustment in cancer, but future research is needed to usefully integrate the topics of cancer and facial difference.

This review was limited by the lack of multiple raters during the analysis process, limiting the confirmability of the findings. The lack of multiple raters is a common weakness in qualitative synthesis (Shaw, 2012), and quality in this review was nonetheless preserved by supervisory auditing of the analysis process. It is possible that this auditing in itself led to a degree of bias as many of the findings identified here are corroborated by the supervisor’s previous research. Identifying qualitative research on electronic databases is a recognised difficulty due to the lack of qualitative-specific identifiers and key words, leading to a dilemma in sensitivity versus specificity (Shaw, 2012). Consequently, it is possible that relevant studies were not included due to a lack of sensitivity in the search terms, however using a greater number of more general terms led to a prohibitively large number of irrelevant results.

Limitations in the literature

Quality appraisal of the papers in this review revealed two studies of questionable quality. Van Doorne et al.'s (1994) study did not substantiate findings with participant quotes meaning that themes are difficult to confirm from the participants' perspective. The dependability of the findings was compromised by a lack of methodological detail: the recruitment strategy was not specified and there was no indication of how themes were drawn from the data. Bonanno and Choi's (2010) study provided sufficient rationale and detail for recruitment and data collection, but omitted to describe the procedure of using GT analysis, thus limiting the trustworthiness of their findings.

One paper was classified as being of fatally flawed quality. Nayak et al.'s (2016) study did not describe how participants were approached, how the semi-structured interviews were conducted or how the data was analysed. No contextual detail to the sample was provided and discussion of the findings was superficial. Participant quotes were provided to support themes which gave a degree of credibility to the findings; however, findings should be interpreted with significant caution.

Two papers were judged to be central to this review due to their high quality ratings and particular relevance to the aims. Turpin et al.'s (2009) study thoroughly described the procedures used throughout the research process, particularly in relation to IPA analysis strategies. The aims to explore sense of self in HNC patients were highly relevant to this review. Konradsen et al. (2009) aimed to explore interactions for those with changed facial appearance after cancer which was invaluable to this review. A stepwise description of the GT procedures used at recruitment, data collection and analysis gave this study high credibility and transferability, and participant quotes alongside in-depth contextual commentary added to dependability.

The remaining papers were of satisfactory quality (Appendix C). More good quality, 'big Q' qualitative research is needed to increase the reliability of reviews seeking to replicate the findings presented here.

Conclusion

The importance of changed facial appearance after cancer varies depending on the stage of the illness and its treatment; in the acute treatment phase survival is the first priority. However, appearance becomes of greater significance in long term recovery and can cause significant social difficulties. Appearance changes impact on the sense of self, and a range of coping strategies are employed to manage the difficulties associated with appearance change. This review has implications for healthcare professionals working with people with changed facial appearance after cancer.

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Section 2

Research Report

The Experience of Facial Prosthesis: An Interpretative Phenomenological Analysis

Abstract

Objectives: This study aims to explore the experience of living with a facial prosthesis. Previous quantitative findings are mixed in terms of psychosocial outcomes for people with a facial prosthesis, and the phenomenology has not previously been explored.

Methods: This study used Interpretive Phenomenological Analysis methods with seven well-adjusted participants with eye, ear and nose prostheses. Substantive semi-structured interviews and a photo-elicitation task were completed.

Results: Themes elicited from the data were: 1) The profound impact of losing part of the face; 2) Living with altered facial appearance can be difficult; 3) The prosthesis reduces the burden of changed facial appearance, to a point; and 4) Adjustment and coping strategies including humour, optimism and supportive relationships.

Conclusions: The experience of living with a facial prosthesis is closely linked with that of having unusual facial appearance. Facial prosthesis can restore normalcy to a point, and a range of coping strategies are assist adjustment.

Practitioner points:

- Peer support, in person or via on-line platforms, should be made available for facial prosthesis patients to share experiences and strategies.
- Prosthetists and other clinicians should be aware of the psychosocial indicators of negative adjustment, such as evidence of stigmatization, avoidance or shame.
- Links between prosthetic and psychology services should be developed to support adjustment.

Introduction

Unusual facial appearance affects over 500,000 people in the UK and is linked with a range of psychosocial difficulties (Changing Faces, 2015). The face represents part of our essential personal and social identity (Cole, 1998): it is through the face that we perceive and make sense of the world and communicate with others. As such the face is necessarily highly visible and hard to disguise. Consequently, changes to facial appearance are often experienced as disruptive to self-identity alongside other psychosocial implications (Katz et al., 2003; Thompson & Kent, 2001). Changing Faces (2017) note that the term “disfigurement”, although commonly used, can be perceived negatively, and terms such as “visible difference” or “unusual appearance” are preferable. The latter terminology will be used in this report.

The psychosocial impact of unusual appearance is widely documented (Rumsey & Harcourt, 2014). MacLachlan (2012) argues that bodily experience is central to self-concept, and that disruptions to appearance can challenge embodied self-identity and lead to a more objectified experience of appearance. A cross-sectional study of 458 participants with a range of visible differences found elevated psychological distress, particularly in social contexts (Rumsey, Clarke, White, Wyn-Williams, & Garlick, 2004). In terms of specifically facial difference, increased depression, anxiety and social anxiety are evident for those with head and neck cancer (HNC: Callahan, 2005), facial burns (Orr, Reznikoff, & Smith, 1989) and facial palsy (Fu, Bundy, & Sadiq, 2011).

Negative reactions from others are common for those with unusual appearance; this leads to body-shame and social anxiety (Kent & Thompson, 2002; Gilbert & Miles, 2014). Scambler and Hopkins (1986) have described concepts of felt and enacted stigma from their work with epilepsy patients. Enacted stigma is the discriminatory behaviours of others in response to difference, and felt stigma is the resultant, internalised shame and expectation of discrimination. Stigma is commonly experienced by those with unusual facial appearance. Strauss et al.’s (2007) cross-sectional study of young adults with facial differences found that 35% experienced staring in the week prior to testing and 11% had got into a fight as a result of their appearance in the previous month. Stone and Wright's (2013) participants with unusual facial appearance were discriminated against in job applications, and Stone and Potton (2014) found that experimentally created "disfigured" faces prompted disgust reactions when rated under anonymous conditions.

However, there is significant variability in adjustment to visible difference (Moss & Carr, 2005) and a growing evidence base describes positive adjustment and coping. Many people adjust well and can draw positives from their experiences (Egan, Harcourt, Rumsey, & Appearance Research Collaboration, 2011; Saradjian, Thompson, & Datta, 2008; Thompson & Broom, 2009). Egan et al.'s (2011) qualitative study with people with a visible difference linked humour, positivity, active coping and downward social comparisons with good adjustment.

The use of a facial prosthesis can impact on adjustment (Ariani et al., 2013). Facial difference may be caused by a congenital condition, a traumatic incident or resecting surgery to treat disease. Surgical reconstruction can increasingly restore appearance, however in some cases the use of a facial prosthesis is required. Reconstructive surgery and prosthetic use aim to recreate a "normal" appearance so as to reduce psychosocial difficulties (Ariani et al., 2013).

Findings regarding psychosocial adjustment to facial prostheses are mixed. Some cross-sectional research indicates high satisfaction with the prosthesis (e.g. Goiato et al., 2008), with satisfaction being higher for osseointegrated compared to adhesive prostheses (Chang, Garrett, Roumanas, & Beumer, 2005). Other studies, however, have found lower quality of life for facial prosthesis wearers compared with the normative population (Klein, Mennekin, Spring, & Rose, 2005; Atay et al., 2013). McBain, Ezra, Rose and Newman's (2013) cross-sectional study with people with an ocular prosthesis found that well-being was linked with psychological factors including optimism and appearance concern, rather than demographic or clinical factors. These studies give some indication of levels of satisfaction, well-being and quality of life, however the phenomenological experience of what it is like to have a facial prosthesis is lacking.

The phenomenology of limb prosthesis use has been investigated. Murray and Forshaw's (2013) meta-synthesis of 15 qualitative studies found that the prosthesis helped individuals to moderate others' perceptions of them, gave a sense of normalcy, and enabled valued identities and activities. Supportive close relationships were key to positive experiences. Some of these studies particularly noted that feeling "different" was minimised by the prosthesis (Saradjian et al., 2008; Murray, 2009). These themes shed some light on the experience of prosthesis use, however the unique psychosocial role of the face is not captured and consequently there is a need for an in-depth examination of the experience of facial prosthesis use.

Qualitative research specialises in exploring experience, building flexible frameworks for understanding phenomena and allowing new theory to develop (Harper & Thompson, 2012). Interpretive Phenomenological Analysis (IPA: described by Smith, Flowers, & Larkin, 2009) is especially concerned with *"giving voice"* to experiences and *"making sense"* of them by suggesting interpretations grounded in accounts (Larkin, Watts, & Clifton, 2006, pp.102). Numerous studies have used IPA to explore unusual appearance (e.g. Thompson, Kent, & Smith, 2002; Thompson & Broom, 2009; Tupin, Dallos, Owen, & Thomas, 2009; Rafique & Hunt, 2015). IPA is particularly useful for enabling exploration of sensitive topics where a nuanced perspective on experience is desired.

This study aims to use in-depth interviewing and interpretive analysis to understand the phenomenological experience of life with a facial prosthesis.

Methods

Design

IPA explores participants' experiences of specific phenomena. Its epistemological assumptions are hermeneutic in nature; it is concerned with how an individual relates to the world, their experience of it, and the meanings they give to that experience (Smith, 2010). IPA is interpretative; it relies on the researcher's interpretation of the participant's account (Larkin & Thompson, 2012). IPA does not test hypotheses but extends theoretical understanding by comparing findings to pre-existing theory. The current study aims to understand the phenomenology of having a facial prosthesis.

Photo-elicitation uses photographs during an interview to facilitate discussion that comes closer to the participant's experience (Harper, 2002). There are several advantages to photo-elicitation (Frith & Harcourt, 2007): increased collaboration, a discussion closer to the participants' meanings, consideration of concepts that are hard to verbalise, and richer, visual data alongside the verbal interview. Photo-elicitation also primes the participant to consider their experience before the interview, thereby preventing loss of data (Smith et al., 2009).

Procedure

Recruitment

Recruitment of an individual or a small group is preferred in IPA. In-depth analysis of fewer accounts is considered more useful than data from many individuals, which may result in a superficial understanding (Reid, Flowers & Larkin, 2005). This study aimed to recruit up to ten participants as this is commensurate with similar IPA studies (e.g., Saradjian, Thompson, & Datta, 2009; Thompson & Broom, 2009; Cadogan & Bennun, 2011).

Two collaborating clinicians in hospital head and neck oncology and maxillofacial prosthetics used their clinic databases to identify participants on the basis of the inclusion and exclusion criteria.

Inclusion Criteria:

- Patients receiving ongoing head or neck prosthetic treatment. Facial prosthesis was defined as any visible prosthesis used on the neck or face, including eyes and ears.

Exclusion Criteria:

- Non-visible prosthesis
- Prohibitive communication difficulties

Participants were not excluded on the basis of other physical or mental health difficulties, or if they were not currently wearing their prosthesis, for example due to discomfort or infection in the prosthesis site.

The recruiting clinicians made initial contact with the participants via a postal pack containing an introductory letter signed by the clinician, an information sheet, a consent form and standardised measures of mood (Appendices F-I). The measures were provided to gain contextual information regarding participants' psychological well-being (Table 1). Measures were the Patient Health Questionnaire (PHQ-9: Krooenke & Spitzer, 2002) and the Generalised Anxiety Disorder scale (GAD-7: Spitzer et al., 2006). Participants could opt-in to be contacted regarding an interview. Participants return their completed measures, consent form and contact details to the researcher using a pre-paid envelope. Participants who elected to take part in the interviews were then telephoned by the researcher and an initial meeting was arranged. This recruitment strategy ensured that the researcher did not have access to participants' personal information until they had given their consent.

Participants

Table 1

Summary of participants

Participant number	Prosthesis type	Cause	Age at acquisition	Age at interview	Gender	PHQ-9 scores*	GAD-7 scores*
1	Partial ear	Skin cancer	76	86	Male	0	0
2	Eye	Trauma	16	78	Male	0	0
3	Eye	Trauma	36	67	Male	0	0
4	Eye	Trauma	14	58	Male	2	1
5	Nose	HNC	53	71	Female	0	0
6	Full ear	Skin cancer	68	74	Male	1	1
7	Full ear	HNC	66	73	Male	0	0

*Scores of 0-5 represent the "mild" clinical range

Seven participants were recruited, aged between 58 and 86 at the time of interviewing. The one female participant had a full prosthetic nose; three of the male participants had full or partial prosthetic ears; and the remaining three participants had prosthetic eyes as a result of traumatic accidents. All participants were White British with English as their first language, and they were all married or in a long-term relationship. Two participants were in full-time employment and the remainder were retired from full-time employment. No current physical or mental health problems were reported – all participants scored at the lower end of the "mild" normative range on the PHQ-9 and the GAD-7. Table 1 summarises key demographic details of the sample.

Data Collection

There were two meetings with each participant. The first meeting served to introduce the study, ascertain demographic details and clarify instructions for the photo-elicitation task (Appendix

G). Participants were instructed to take photographs representing some aspect of their experience of having a facial prosthesis. This could be of anything; photographs did not need to include the prosthesis or the participant necessarily. Service user involvement (SUI) at a HNC support group indicated that participants would be amenable to the task and may prefer to use their own cameras. There was some confusion about the nature of the task, and it was anticipated the photography task might provoke some anxiety. The introductory meeting was therefore deemed necessary to comprehensively explain the task and answer any questions. The substantive interview was conducted roughly two weeks later. The interview schedule employed open questions which did not assume level of adjustment or impact of the prosthesis (Figure 1), although sometimes more directive questions were used to clarify an aspect of the experience already raised by the participant.

Main interview:

1. Tell me about what it's like for you having a facial prosthesis.
2. What's it like for you to use your facial prosthesis when you are on your own?
3. What's it like for you when you are around other people?
4. What's your experience of day-to-day life having a facial prosthesis?

Prompts: Has it always been like this for you? Can you tell me more about that? How did/does that feel for you? What did/does that mean for you?

Photo-elicitation:

1. Can you describe what you have photographed here?
2. Why did you take this photo?

Prompts: What does it mean for you? What were you thinking about when you took this photo? What did you want to tell me or be reminded of when you took this photograph?

Figure 1. Interview Schedule.

The schedule was piloted with another qualitative researcher to check for coherency and bias. The first participant interview was used as a pilot; the data generated was relevant to the aims of the study and feedback regarding the questions was positive, so this data was included in the study.

Copies of the photographs were kept by the researcher throughout the analysis process but are not included in this report in order to protect participants' anonymity. The primary function of the photographs was to facilitate discussion – therefore their meaning is largely captured within the verbal interview.

Interviews lasted between 35 and 90 minutes and were audio-recorded on encrypted devices. The first interview was transcribed verbatim by the researcher and remaining interviews were transcribed by a University-approved transcribing company.

Analysis

Interview data was analysed using IPA techniques (Larkin & Thompson, 2012). Transcripts were read while listening to the recording to check transcription accuracy and enable the researcher to become immersed in the data. Initial themes were noted on a line-by-line basis including linguistic, descriptive and conceptual interpretations. Emergent themes summarising the participant's experience and the researcher's interpretation were listed in Microsoft Excel, alongside transcript line numbers so that themes could be linked to the data. Themes were adapted and reordered into conceptual hierarchies to identify over-arching themes (Appendix J). The data from each participant were initially analysed separately to preserve individual phenomenological experiences, then themes were compared across participants. Finally the frequency, importance and conceptual accuracy of over-arching themes was compared with the transcripts to ensure that the findings remained close to the original data.

Reflexivity

Harper and Thompson (2012) describe reflexivity as awareness throughout the research process of how the researcher's responses, assumptions and beliefs interact with the data and inform interpretation. A researcher's interpretation cannot represent an entirely direct or complete understanding of the participant's experience; therefore, the role of researcher reflexivity must be considered; this also adds richness to the analysis (Biggerstaff & Thompson, 2008). Strategies were employed throughout the research process to account for reflexivity (Finlay & Gough, 2008). First, a reflexive diary was kept in which the researcher noted down reactions to the data, assumptions which had been challenged or confirmed by the data, the emotional impact of interviews and expectations for continuing data collection and analysis. Second, group supervision with other qualitative researchers[1] used the reflexive diary alongside blank and annotated transcripts to prompt deeper reflection on emergent themes and consider the researcher's unique impact on analysis (Appendix K).

Quality Control

Quality control in qualitative research seeks to ensure the validity of findings by limiting bias and accounting for rigour in the methodology (Yardley, 2000; Larkin & Thompson, 2011). To control for quality during interviews, the researcher used tentative summarising of experiences to verify understanding. The research supervisor audited the themes and three annotated transcripts to scrutinise the rigour of analysis and ensure the findings were traceable. Discrepancies in interpretation were discussed until agreement was reached. Anonymous excerpts from transcripts are incorporated into the results to allow transparency of the interpretative process. Another transcript was also audited by two colleagues[1] familiar with qualitative methods in the same way (Appendix K).

Ethical Considerations

Eethical considerations for qualitative research are outlined by Thompson and Russo (2012). These relate to confidentiality, informed consent, avoiding harm and managing the dual-role of clinician and researcher; these were considered throughout the research. None of the participants

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[1] Trainee Clinical Psychologists

raised difficulties they were not already receiving support for, however contact details for support groups and healthcare providers were on hand for this possibility. To maintain researcher safety, the University of Sheffield guidance for conducting home visits was observed.

Ethical approval was obtained by proportionate review through the NHS Integrated Research Application System, the Health Research Authority, and individual NHS trusts prior to contacting participants (Appendices L-O). Ethical approval was not granted to include photographs in this report.

Results

Figure 2 summarises the over-arching and subordinate themes that emerged from the data. Reflexivity issues are presented alongside the results.

All participants apart from one took part in the photo-elicitation task. In each case, the photographs facilitated more in-depth discussion, adding richness and accuracy to the understanding of experience. Table 2 gives examples of photographs and how they added to the analysis. Photo-elicitation was approached in different ways. Three participants took photographs specifically for the research project – in each case they photographed themselves and their prostheses. Three participants used pre-existing photographs, including images of themselves at different time points and of people and places that illustrated part of their experience. The participant who did not take part said that he could not think of anything to photograph, as he does not think about his prosthesis on a day-to-day basis. One participant requested a disposable camera; the rest used their own cameras.

1. **The profound impact of losing part of the face**
    - 1.1 Losing part of the face is life-changing
    - 1.2 The added burden of cancer
2. **Living with altered facial appearance can be difficult**
    - 2.1 Negative self-image
    - 2.2 Self-consciousness and unwanted attention
    - 2.3 Negative treatment from others
3. **The prosthesis reduces the burden of changed appearance, to a point**
    - 3.1 Prosthesis is enabling and restores normalcy
    - 3.2 There is a limit to the benefits of the prosthesis
    - 3.3 Practical issues that continue to be problematic
4. **Adjustment and coping strategies**
    - 4.1 Humour
    - 4.2 Stoicism, optimism and giving back
    - 4.3 Positive comparisons
    - 4.4 Supportive relationships are essential

Figure 2. Over-arching and subordinate themes

Table 2

Examples of photographs and supported themes

Description	Summary of discussion	Supported themes
P1: Photograph of ear with prosthesis	It is hard to tell that there is a prosthesis on the ear, descriptions of the process of making the prosthesis	Supportive relationship with prosthetist, prosthesis brings normalcy
P2: Photograph of face without eye prosthesis	Participant's emotional reaction to seeing the photograph	Negative self-image
P4: Group photograph of daughter's wedding	An enjoyable social situation that he participated in despite normally feeling self-conscious in groups	Self-consciousness, adjustment and coping, supportive relationships
P6: Photograph of barber's shop	Descriptions of an incident which occurred at the barber's shop	Humour

1. The profound impact of losing part of the face

All participants gave detailed narrative accounts of how the loss of their eye, nose or ear came about. For cancer patients this included discovery of the symptoms, the process of seeking help and escalating medical intervention:

> P6: *"It all started on this ear. Went to a dermatologist, who didn't think it was much. ... eventually I had to go and see a consultant and he suggested that he'd cut a 20mm piece out…sent it off for a biopsy. It came back and he says, 'I'm sorry…your ear has got to come off.'"*

The remaining participants described the context, build-up and aftermath of the accident in which they lost their eye:

> P2: *"My mother told me on the day I lost my eye not to play with the air rifle but I was taking no interest ... I was in a shelter doorway putting an air rifle pellet into the rifle when I felt something hit me in my left eye … I put my hand to my face to find it covered in blood. I was taken to the ambulance room …"*

These accounts were unprompted, suggesting that the experience of having a prosthesis is bound up in the story behind the loss of part of the face. This ties in with other themes in which the prosthesis acts as a constant reminder of the disease or trauma: being asked about the prosthesis reminds participants of the story behind it, and prompts a factual recounting of that experience. One participant explained that over time he has memorised an explanation which has become a habitual strategy for coping with embarrassment;

> *P2: "I've had it for so long it's just like running a short lesson with somebody … I just tell them what they want to know and not feel embarrassed about it"*

Reflexivity: I wondered whether this 'rote-retelling' was impacting on the research interview. This participant willingly shared a lot of detail but it was harder to access the underlying emotion. I wondered if this was a learnt social strategy to reduce difficult feelings by managing my/others' curiosity. In future interviews, I was more able to notice participants' use of practiced narratives and ask them about their experience of "making explanations".

1.1 Losing part of the face is life-changing

The participants who acquired their prosthesis in early life as a result of trauma described the change to their aspirations and hoped for trajectories to their lives as a result of losing an eye.

These descriptions followed the unprompted narratives of how they acquired a prosthesis. Looking back with regret and wondering how things might have been different were shared experiences, however participants also took pride in defying expectations and acknowledged that the accident had led to different opportunities:

> *P2: "I was told I was unable to go into the armed forces ... the one aim in my life had been fouled up" ... "I was offered a post as an instructor ... it opened my eyes the things I saw"*

Thus, the prosthesis was a reminder, sometimes of regretful loss and sometimes of gratitude and self-pride:

> *P4: "Of course I wanted to be a police officer and then this happened and that went out the window" ... "I showed them that they were wrong. I got a grade one CSE in physics, because I loved science"*

One participant who lost his ear as a result of cancer also experienced a change in the planned trajectory of his life. He received his diagnosis shortly before retiring and he feared losing the future he had hoped for:

> P6: *"But it was all just before I retired and I thought, 'Oh no, this is a good start to retirement, starting with cancer...I never expected this"*

For this participant, being asked about his prosthesis was a reminder of how the cancer had changed the course of his life.

1.2 The added burden of cancer

This theme was unique to those participants who acquired their prosthesis through cancer, for whom the disease was the focal point of their experience of the prosthesis. They described a long and difficult journey, beginning with worry at the discovery of symptoms and progressing through shock at the diagnosis, the fear of surgery and the discomfort of recovery. Further operations were required to fit osseointegrated magnetic prostheses, so having a prosthesis was experienced as an extension of the cancer journey. The journey was seen as a battle to be fought, or a series of hurdles to be overcome. In this sense, having a prosthesis gave participants a survivor-status and acted as a symbol of victory over cancer:

> *P5: "Apparently I'd got a 30% chance of surviving, and that was all I'd had … I had a little talk to myself and thought, 'Right, you are going to fight this.'"*

Cancer was experienced as a common and yet terrible phenomenon and survival was the first priority. Participants felt that the discomfort of treatment, the changes to appearance and the resultant acquisition of a prosthesis were acceptable prices to pay for survival:

> P1: *"I'm lucky to be here, still relatively minor thing [prosthesis] if we put things in perspective"*

> P6: *"It's horrendous. Absolutely horrendous. Now, this word, C, is trauma."*

The presence of cancer acted to put other difficulties into perspective with the overall priority of staying alive. The experience of having a prosthesis was therefore defined positively in relation to the benefits of continuing to live in the world:

> *P5: "I'm still here. I can see my grandchildren now … I'm so thankful for what they did because I'm seeing things I may not have seen because I'd have been dead"*

Reflexivity: I was particularly struck by P5's positivity and gratitude, possibly because she was the only woman and the only participant with a nose prosthesis. I wondered if I was seen as a healthcare professional, and if so did that influence how participants talked to me? Did their "survivor-status" lead to a sense of obligation to be positive? In future interviews, I was careful to introduce my role as a researcher rather than a clinician.

2. Living with altered facial appearance can be difficult

All participants, regardless of what type of prosthesis or how it was acquired, talked about the experience of having unusual facial appearance. This was almost exclusively described as negative, both psychologically and socially. Most descriptions related to being without the prosthesis, even though this was not expressly asked about, suggesting that the experience of having a prosthesis can be defined in comparison with not having it. Thus, having unusual facial appearance is an inherent part of having a facial prosthesis.

2.1 Negative self-image

All participants felt that they looked "different" as a result of their altered appearance. Participants felt that without the prosthesis they were aesthetically inferior to others. They felt shock, horror and disgust at their appearance, and avoided looking at themselves in the mirror. Thus, the experience of having a prosthesis can be understood in the context of these negative constructions of the self:

> P1*: "I was pretty horrified ... it looked terrible without a dressing on ... It wasn't very attractive"*
>
> P2: [Looking at a photograph of self without prosthesis] *"Oh, crikey ... Oh, it's a scared Frankenstein. I didn't think I could be so horrible"*
>
> *P5: "I didn't even look at myself for three months ... I didn't want to look at myself"*

Participants described themselves as looking unbalanced and incomplete without the prosthesis, and felt that they were a diminished version of themselves:

> *P6: "Rather than see just one side with an ear and other side without one, I think that was important"*

2.2 Self-consciousness and unwanted attention

Self-consciousness was a recurring theme for all participants, to varying degrees. Self-consciousness was experienced both with and without the prosthesis, suggesting that the negative self-image caused by changed facial appearance continued to pervade the experience of wearing a prosthesis to some extent. Feelings of being conspicuous and garnering attention as an object of curiosity were common and led to embarrassment:

> *P3: "I was a little bit conscious about other people actually noticing it"*

Participants wondered what others might think about them because of their appearance, and in some cases avoided social situations and used strategies such as concealment or distraction with hair or jewellery in order to reduce the feeling of self-consciousness:

> *P2: "I often wonder, when it's happened and they've gone away, what they're thinking about it"*
>
> *P5: I get a bit conscious of it when I go out and ... if someone's looking, I think, 'Oh dear, somebody's noticed' ... I didn't go out much then"*

Participants felt responsible for others' reactions, and felt fear and guilt about causing upset to others, particularly family members, on account of their appearance. This reinforced their view of themselves as frightening, abnormal and the subject of stigma:

> P5: [After family member had seen face without the prosthesis] *"I felt awful ... And I said, 'I'm very sorry ... you shouldn't have seen this ... you'll never see it again'"*
>
> *P7: "I wanted to go over to him and just tap him on the shoulder and say, 'It's alright, dear.'"*

Receiving unwanted attention from other people was the most commonly described social experience for all participants:

P1: "I would have been embarrassed, yeah … without [the prosthesis] it would draw attention to me and make people look twice"

This included intrusive questions about what was wrong with them, unwanted sympathy and pity, and the burden of repeatedly offering explanations for their appearance. In this way, the experience of having a facial prosthesis was burdensome because of the need to manage others' reactions:

P3: "I suppose deep down I was thinking about the other people that were looking. Rather than keep saying, you know, 'what have you done?' and having to explain all the time"

Unwanted attention reinforced feelings of inferiority and abnormality, yet it was also experienced as an inevitable reaction and therefore something to be either avoided or endured. This is evident in the repetition of phrases such as "just got to get on with it" and "but it doesn't bother me" throughout all interviews, suggesting a feeling of resignation around being seen as different.

Others' reactions could vary considerably and were therefore hard to predict, so participants could feel apprehensive and avoidant about meeting new people;

P4: "I'm a little bit wary because I don't know how they're going to react … I don't know how this newcomer will react to such a thing"

Reflexivity: P4's anxiety about my reaction may have impacted on his responses in the interview. I felt that he was "on-guard", especially at the beginning of the interview. His past experiences of stigma make some sense of this. During the analysis, I considered P4's responses in the light of his social anxiety and his "standoffish" presentation, particularly in making sense of the social situations he described.

2.3 Negative treatment from others

Most participants experienced overtly negative behaviours from others on account of their altered appearance. Although this occurred predominantly when not wearing the prosthesis, it continued to happen to some participants when wearing their prosthesis. Behaviours included staring, being talked about, name-calling and derogatory assumptions or accusations about the cause and about the ability of the participant:

> *P2: "She called me some vulgar names ... I felt very small, inadequate, if you like, having been called that by an ex-girlfriend"*
>
> *P5: "I suppose because I'd had some funny reactions ... [a woman] said, 'has he been hitting you?' And she meant it, she wasn't laughing or kidding"*

In one case, a participant was verbally and physically assaulted because of the way that he looked to the point of causing him to feel unsafe in his home and even to consider suicide:

> P4*: "Lots of name calling. I have been assaulted ... They had always taunted me about the fact that I'd only got one eye, call me names, things like that, throwing things at me ... I believe I would have been killed on that estate ... my thoughts were really towards attempting suicide"*

These negative reactions were upsetting and undermined participants' self-worth and confidence. The experience of being "different" was reinforced by being avoided by others, which participants accounted for as a result of others feeling awkward and uncomfortable around someone with altered appearance:

P7: "If you went anywhere ... you can see people going [mimes peering and staring] ... then they say, 'twit, twit, twit" [mimes people muttering amongst themselves] ... But people are so embarrassed themselves that they look but they don't want to talk to you"

Such negative reactions contributed towards participants feeling responsible for others and needing to moderate negative reactions.

3. The prosthesis reduces the burden of changed appearance, to a point

When asked about their prosthesis, participants initially talked almost exclusively about their changed facial appearance. When prompted to consider more directly the role of the prosthesis, all participants described it in highly positive terms:

P5: "It was like somebody had given me all my Christmas presents in one ... Yeah, it was absolutely wonderful and I hugged [the prosthetist]. I said, 'This is absolutely wonderful'."

The positive impact of the prosthesis as sophisticated concealment of changed facial appearance seemed like an obvious experience that went without saying for participants. Again, the experience of having a facial prosthesis is inexorably tied to the experience of altered appearance.

The prosthesis was seen as a symbol of hope and healing; although others did not always notice it, it was a reminder to the participant of their survival and adjustment, and gave them a unique, special identity:

P1: "I am an example of what can be done, you know ... as far as I'm concerned, I couldn't have hoped for a more successful outcome"

3.1 Prosthesis is enabling and restores normalcy

The prosthesis was seen as "part of me" by some participants and as restoring their previous, desired selves. Embodiment of the prosthesis was evident in comments referring to the prosthesis as a body part which had been lost but was now regained:

P6: "Oh, that's brilliant. That's absolutely amazing, you know. You'd got your ear back. I could hear and I'd got the actual ear back"

P7: "It's part of me now. And, you know, when I come, that comes, as simple as that."

Several participants said that they often forgot they were wearing their prosthesis. One participant said that his eye prosthesis was so much a part of him now that he could go for days without thinking about it. For others, however, the embodiment of the prosthesis was fragile, as illustrated by contradictions in their accounts. One participant said, "it's just a plastic ear as far as I'm concerned", but shortly afterwards said it had "become part of me." Similarly, other participants described the prosthesis as being "part of me", but frequently chose not to wear the prosthesis either at home or in social situations.

Self-image was restored when wearing the prosthesis; participants were satisfied with their appearance and confident in social situations. Having a lifelike prosthesis enabled participants to feel more truly themselves, so that they could engage in valued social interactions without feeling defined by their appearance:

P7: "I wasn't a bloke with one ear that was muscling in on anything ... I was one of them, I'm fitting in, I'm not a freak; I'm fitting in. And I think that makes it a better feeling."

With the prosthesis, participants felt confident and enabled to participate in activities without feeling embarrassed about being "different". Rather than feeling self-conscious, participants could forget about their face and get on with living their lives:

P1: "It gives me a feeling of wellbeing, if you like, it makes me feel normal, or as normal as possible, I suppose. But it makes me feel, well, outwardly like everyone else"

P4: "It makes me feel a bit happy because it gives me a sense of normality ... which of course raises my personal feeling and I get on with whatever I'm doing a little better ... helps boost me, I can get on with life, get on with work"

The prosthesis appeared to act as a concealment of the altered appearance, which gave a sense of agency over how participants presented in the social world, rather than feeling controlled by their appearance. In this way, the experience of having a facial prosthesis was of being unburdened of some of the consequences of altered appearance:

P5: "Well, you could glance at yourself in the mirror all the time and think, 'I can make that hole go away now,' and it was wonderful."

Having a life-like, natural looking and securely fitting prosthesis was important. These factors maximised participants' confidence to engage in valued activities without worrying about explanations or negative reactions if the prosthesis was noticed or fell off:

P3: "It's made me look more natural to other people ... I suppose it's the confidence and that, but rather than asking what's up, 'What have you done?'"

Participants seemed to particularly value occasions when the prosthesis was mistaken for the real body part, particularly as this meant there was no need for explanations. Thus, the effort of recounting their story yet again was minimised and participants could engage with others more freely. The joy that some participants described when their prosthesis passed as a real body part shows the significant value of restored normalcy:

P1: "...it was brilliant ...I measured the success because people weren't aware of it ... life would have been very, very different ... more uncomfortable, self-conscious"

P7: "Talking to me this side with my blank ear ... and he don't know and I'm just sat laughing, knowing that I'd got a false ear"

3.2 There is a limit to the benefits of the prosthesis

Although the benefits of the prosthesis were lauded by all participants, the experience was not always entirely positive. Specific disadvantages were rarely raised - limitations were more likely to be mentioned obliquely, possibly suggesting that it was important to participants to maintain a positive narrative of their experience, or that the negatives were insignificant next to the positives.

Some participants felt that the prosthesis could never be as good as the real thing and would only ever be a lifeless replica of what they had lost. This was especially true for the participants with eye prostheses, as the prosthesis could not restore vision. Thus, the experience of having a facial prosthesis could not fully counteract the loss of self caused by the cancer or trauma:

> *P6: "I'm always aware that this is false and this isn't. There's no feeling there and I'm aware of that every day"*

In the photo-elicitation task, one participant showed a photograph of his glasses from the inside, and another cropped to show just half of the image. This illustrated his frustration at the discrepancy between what he can see and what his outward appearance with the prosthesis implies he can see. For him, the prosthesis could be experienced as presenting a "false" or incongruent representation of the self.

As previously mentioned, the prosthesis could act as a constant reminder to the participant of their altered appearance, their physical and social disability, and the traumatic processes they endured in acquiring the prosthesis. Thus, having a facial prosthesis could not fully reverse the impact of the past in the participant's experience.

> *P2: "A stupid mistake, stupid mistake on two people's part, mine and the guy who did it ... it's just a constant reminder"*

> *P4: "It just reminds me that I am different ... It's just a constant reminder of that"*

One participant felt that his eye prosthesis was a risk to him as it made him more vulnerable to injury:

P4: "The softest part of the human skull is between the eyes, which is where it sits, which is probably why I got the fractured socket..."

This resulted in increased anxiety when playing with his grandchildren, and necessitated guilt-provoking conversations to warn them against hitting his eye. Thus, having a prosthesis could not remove feelings of responsibility for others' behaviour in relation to the prosthesis.

3.3 Practical issues that continue to be problematic

Having a facial prosthesis involved ongoing practicalities for all participants, although the weight of the practical burden varied widely. Some participants did not have any concerns with the maintenance involved in having a prosthesis, while others expressed a sense of unfairness and experienced the practicalities as tiresome:

P2: "In dry season I have to make sure not to get grit in it. It has to be cleaned. I have to clean it every day ... I have appointments every six months"

It was common to have multiple prostheses, in case of loss, or to use while traveling when cleaning was difficult:

P1: "So now ... if I travel anywhere I take a couple of spares and [my wife] has one in her handbag normally'

As a result of negative self-image and fear of negative reactions, participants needed to be more prepared for everyday activities and make thorough plans to reduce the likelihood of distressing situations. Some anxiety was evident about being seen without the prosthesis, and the practicalities of managing this anxiety were burdensome:

P5: "If the doorbell rings, I know that it's there. I can pick it up, put it on, you know ... always have my prosthesis and glasses ready because whoever knocks at that door ... you need to look your best"

Participants needed to adjust their daily routines to facilitate frequent cleaning of the prosthesis and prosthesis site to prevent infection – sometimes this was experienced as inconvenient and frustrating;

P5: "Some mornings, especially if I've got a bad cold, you get a lot of mucus and it's all got to be cleaned out"

Some participants also found it hard to remember to clean their prosthesis, and relied on prompts from family members:

P3: "I mean sometimes I forget I've got it in ... they recommend no longer than a week, just to clean it, but like I say, I forget sometimes"

4 Adjustment and coping strategies

A wide range of cognitive, behavioural and social strategies were employed by participants to cope with the difficulties associated with unusual facial appearance and to aid adjustment to the prosthesis. Several factors emerged from participants' accounts which impacted on adjustment; some of these were dispositional while some were learnt and adapted strategies.

4.1. Humour

Most participants identified humour as an important strategy to aid acceptance of both the altered appearance and the prosthesis. This applied both to acceptance by the self as well as from others. Indeed, a sense of humour about the prosthesis was seen as crucial to adjustment and several participants felt that they couldn't have managed without it. The use of humour was experienced as a deliberate choice, a positive alternative to getting upset:

P6 "You've got to have humour. You can't go about with a serious thing all the time ... you've got to have humour. You've got to have a laugh with it."

P7: "You don't get concerned and upset about it ... you just have a good laugh about it. I mean, laughter's the best medicine, isn't it?"

One participant coped with potentially embarrassing circumstances by laughing and taking pleasure in creating a bizarre social situation. This approach seemed to help him to continue interacting with others in these situations; enabling him and his social partner to acknowledge his differentness without feeling threatened by it:

P2: "Well, I almost burst out laughing when I asked him to pick the prosthetic eye up, because at that time it seemed amusing to me ... if I could have seen his face ... [laughter]."

Several participants enjoyed using their prosthesis to play pranks on other people. Sometimes this was accidental and sometimes it was deliberate; either way, these acts seemed to boost self-esteem through entertaining a watching audience and exerting power over others through the idiosyncratic trait of their prosthesis:

P4: "...my eye came out, straight into his cup... he kept taking a drink of his tea until he got to the bottom and it was staring at him ... everyone else just basically fell about laughing because they'd seen what I'd done. I thought, 'Well, they've started laughing with me again.'"

Through humour, participants could be confident and open about their difference, enabling them to foster a positive identity of themselves as special and unique:

> *P6: "…so, she's snipping away and she pulls it down to get to the back and it comes off. And I went, 'Oooh!' and I've never seen a face…she just ran out of the shop … And everybody in the shop was just laughing, it was hilarious [laughter]."*

Reflexivity: I found these stories very funny, and these parts of the interviews were characterised by genuine laughter from both myself and the participant. I noticed that I subsequently felt more connected and at ease discussing the prosthesis with the participant, and it struck me that humour could be an effective social strategy. Having noticed this, I was more aware of my own interpersonal reaction to humour in the remaining interviews and when reading transcripts.

Participants used humour about their prosthesis to put others at ease and to break uncomfortable silences in which others did not know what to say or viewed the participant as frightening because of their appearance:

> *P4: "…making fun in that sort of way is also part of my defence … other people; they can be a bit wary when they find out. So I will start by making a bit of a joke about myself to get them at ease"*

Sometimes the prosthesis was used to put others at ease with unrelated problems, such as reassuring a young girl going to get her ears pierced. In these cases, the prosthesis was used as a social tool for managing difficult situations;

> *P1: "I would say sometimes in jest … a girl talking about pierced ears or something like that, I'll say, 'Well, how about mine?'"*

4.2 Stoicism, optimism and giving back

Participants frequently described a stoical attitude towards their altered appearance and prosthesis, with many using the phrase “getting on with it”. They were often very matter-of-fact about their situation, and often emphasised their decision not to be “bothered” by their appearance:

> *P6: “You take the bandage off and you’re, ooh, yeah, shock, but there again I thought, ‘I’ve got to live with this, so get on with it’ ... I’m not bothered what I look like, what people think I look like. I’ve got to do this and carry on.”*

Despite this, none of the participants preferred not to wear their prosthesis, suggesting that this stoical approach may have been undermined without the availability of a lifelike prosthesis to reduce the negative social impact of altered appearance. Nonetheless, a stoic approach reinforced participants’ self-identity aside from appearance, enabling them to see themselves as more than their appearance:

> *P3: “But I just get on with it. It’s like when I get a job at work, just get on with it ... just get on ... It’s just cosmetic, yeah. Doesn’t alter me.”*

Positive coping was also accounted for by dispositional optimism. Participants who identified as being naturally optimistic in the past continued to focus on and work towards positive futures in which they could continue finding meaning in relationships and activities. This optimism for the future seemed to increase wellbeing in the present moment:

> *P5: “There can be light at the end of the tunnel, and, you know [talking about cancer] takes me back but I don’t dwell on that. You should dwell on the future.”*

Confident personality traits also enabled participants to envisage and enact positive futures. Some participants could imagine potentially daunting situations and feel confident in their ability to cope, a mind-set which was unchanged as a result of their altered appearance:

> *P7: "I'm the sort of person that you can take me into a room of total strangers and it wouldn't bother me one iota."*

Another strategy involved finding fulfilment through taking on a helping role. Four participants held an official role in a teaching or healthcare setting providing support to others, and all the participants described incidents from their personal lives of sharing their experiences to help alleviate others' distress. Helping roles added a positive meaning to the negative experiences of trauma, disease and altered appearance, and increased self-worth beyond appearance:

> *P5: "There was this one lady … she said to me after I'd seen her, 'You've really helped.' And I said, 'Well, thank you for telling me that, because I feel better seeing someone and I feel better because I can help you.'"*

All participants stated that they were keen to take part in this research in order to support any efforts that might lead to improved support for people in similar situations.

4.3 Positive comparisons

Participants experienced gratitude and relief that their situation was not as bad as it could have been by comparing themselves to others in worse circumstances. There was not an objective scale of severity impacting on adjustment; rather, participants had a relative awareness that there was "always someone worse off":

> *P6: "I've been lucky. I've come through it and, touch wood, I've been fortunate. I could have been in the same scenario as them."*

Participants with ear prostheses compared themselves to people with a nose prosthesis, and were thankful not to be in that situation. However, the participant with a nose prosthesis compared herself to others who had lost their nose but had not received an all-clear from the cancer, and was consequently thankful for her relative good fortune:

P1: "[The prosthetist] said he'd done a complete nose for somebody. Now that's a different matter altogether ... anywhere on the face other than the ear [would be worse]"

There were differences in how age and gender were perceived to impact on adjustment. Men who acquired their disfigurement later in life described relief as a result of their perception that changed facial appearance would be harder to live with for younger people and for women:

P1: "I imagine that some people might feel very differently about it, women more than men"

P6: "Obviously, it'd be a lot more important if I were younger ... a friend was in contact with a young woman at 17 who had just had her ear off ... Now, at 17 in a girl, I mean terrible."

In line with this perception, the female participant was the only one who mentioned that appearance was importance to her before the cancer surgery.

Reflexivity: How did the fact that I am a young woman without a facial difference impact on these participants' descriptions? I wondered if they might be over-emphasising their positive adjustment to reassure or protect me, and whether they would have even referenced age and gender as a comparison if I had been an older man? Noticing responses to this salient difference between participants and myself added weight to theme 2.2, in which participants feel responsible for others' reactions.

4.4 Supportive relationships are essential

The experience of being supported by others was significant in all accounts. Feeling accepted in valued close relationships, such as family, friends and colleagues, was seen as essential to positive adjustment to both the altered appearance and living with the prosthesis:

> *P5: "My friends were very, very good. They used to come two or three times a week ... [My husband] was an absolute brick, well, he wasn't brick, he was stone. He was brilliant."*

Being accepted by others helped participants to accept themselves, and gave them hope that they could face the future with this support. Ongoing relationships that were not damaged by the changed facial appearance increased participants' awareness of valued aspects of their lives beyond the disease or trauma, or the changed appearance:

> *P3: "When I first met [my wife], she didn't even know ... but, well, eventually I told her ... she was surprised but other than that she just took it in her stride"*
>
> *P4: "[Telling people] is not hard ... I've got a wife that is even more so proud of me know ... and my kids, just got a granddaughter..."*

Warm curiosity about the experiences of other people with a facial prosthesis was expressed by several participants, as was a sense of solidarity with other people who experience "challenges" in life:

> *P4: "I guess it's the same for anybody with any form of challenge ... so, I'm not alone, and they probably feel exactly the same way that I do"*

One participant in particular valued hearing about others' difficulties and took comfort in the shared nature of suffering. For this participant, conversations came about through a combination of others' curiosity and her willingness to talk openly. The social strategies she had learnt since acquiring her prosthesis brought her to a place of connection with others that she had not experienced before her illness:

> *P5: "You know, when you start talking to some people ... somewhere along the line, when they start talking, they've had their own sadness ... and you think, 'Well, they've been through it as well.'"*

Being listened to, being treated normally, being offered sensitive and empathic sympathy, and not being avoided by others were all characteristics of supportive and accepting relationships that contributed to positive adjustment. Humour was used by others as well as by the participants, which helped adjustment; for some, "banter" had always been a central part of their interactions with others, so receiving "banter" about their prosthesis gave them a continuing sense of belonging despite their changed appearance:

> *P6: "Obviously I got a bit of flack when I first went back [to work]. They were all, 'Oh he's back, look at his ear.' It was smashing ... no nastiness, no nothing."*

Relationships with the care team, especially the prosthetists, were another prominent feature in participants' accounts. Due to the highly personalised and ongoing nature of maintaining a prosthesis, participants developed relationships akin to friendship with their prosthetists:

> *S6: "With the time that we've been going, I've got quite a rapport. I can walk in that place anytime. You're made welcome. You can have a chat with them about anything, not just about your case, anything."*

Characteristics of positive care included a collaborative approach and shared decision making, which led to sense of agency and empowerment for participants:

> *S7: "Well, good old [prosthetist's first name] and I, we got our heads together and we remodelled it so that it fitted again"*

All participants expressed a lot of admiration and appreciation for the skill of their prosthetist in creating such life-like prostheses:

> *S2: "...the time it takes to do it and get it as good as it is. And it's quite spot on actually. He does a damn good job."*

> *S3: "Absolutely brilliant, yeah, because I mean they've even got the little thread veins in, all that, it's a really, really good job."*

A natural looking prosthesis was crucial to restoring normalcy, so participants were extremely grateful for the prosthetists' workmanship which made this possible.

Discussion

The aim of this study was to explore the experiences of people living with a facial prosthesis. The themes elicited from interviews were: 1) the profound impact of losing part of the face; 2) living with unusual facial appearance can be difficult; 3) the prosthesis reduces the burden of unusual appearance, to a point; and 4) adjustment and coping strategies. This study provides unique insight into the experience of living with a facial prosthesis.

Experiences differed to some degree depending on what had caused the loss of part of the face, although there were also considerable similarities in accounts. Those who acquired their prosthesis through a traumatic accident described in more depth their regret for what their life might have been if not for the accident. These participants had each lost an eye, which resulted in visual and functional as well as appearance concerns, and the accident occurred much earlier in life compared with the cancer group. As a result, these participants felt that the whole course of their lives, including careers and relationships, had been shaped by the accident and resultant prosthesis use. By comparison, the cancer group experienced the acquisition of the prosthesis as an interruption and threat to a life already established. A personal narrative around the horror of cancer had a particular impact on cancer survivors' experience of living with a prosthesis. Survival as a priority over appearance has been found among other survivors of cancer resecting surgery such as limb amputation, mastectomy and glossectomy (Piot-Ziegler, Sassi, Raffoul, & Delaloye, 2009; Fang, Shu, & Fetzer, 2011; Zhou et al., 2015). The importance of survival for cancer patients impacted on their subsequent experience of living with a facial prosthesis. Cancer patients were more likely to see their prosthesis as a symbol and reminder of survival and victory over the disease. While being reminded of the cancer journey could be distressing, ultimately the reminder seemed to prompt hope, gratitude and putting difficulties into a positive perspective.

Issues of felt and enacted stigma as a result of unusual facial appearance were common. The wide-ranging stigmatizing reactions from others, internalised feelings of shame and self-consciousness, negative self-image**,** the self as an object of curiosity, feeling incomplete, social apprehension and avoidance, and inferiority compared with society's standards of normality are corroborated by much previous research (e.g. Kent & Thompson, 2002; Strauss et al., 2007; Gilbert & Miles, 2014; Stone & Potton, 2014)**.** The ongoing significance of stigma in participants' accounts suggests that living with a facial prosthesis cannot be separated from having unusual facial appearance and associated social difficulties. The prosthesis was highly valued for restoring a degree of normalcy to social interactions and improving participants' confidence and wellbeing in themselves, however it did not fully remove the burden of stigma for most participants.

Notwithstanding the negative experiences of trauma, disease and stigma, the sample in this study was notable for positive adjustment and low psychological distress. Participants' positive experiences of their prostheses were presented in contrast with the negative backdrop of altered appearance. Thus, for these participants, the benefits of the prosthesis were always linked with the negatives of altered appearance.

The main benefit of the prosthesis was the renewed sense of normalcy it brought. Several studies report increased feelings of normalcy as a result of limb prosthesis use (e.g. Gallagher & Maclachlan, 2001; Murray & Fox, 2002; Saradjian, Thomson, & Datta, 2008). Lundberg, Hagberg, and Bullington's (2011) qualitative study with participants with osseointegrated limb prostheses found that the prosthesis marked a change from feeling different to feeling normal. A preference for an osseointegrated prosthesis was apparent in the current study, possibly because practicalities of attaching the prosthesis and fear of it falling off are minimised, therefore increasing the sense of normalcy. Crompvoets' (2012) exploration of the experience of breast prosthesis following mastectomy supports the finding of a prosthesis' limitations in restoring normalcy, which fell short of participants' hopes. The author suggests that this finding is explained by narratives in health care settings which reduce the concept of recovery to physical restoration without accounting for psychological or social processes throughout the duration of the disease and treatment.

MacLachlan (2004) posits that prosthetic embodiment involves identification with the prosthesis such that it is experienced as part of the self, and the functional and emotional boundaries between the body and the prosthesis become indefinite. Some participants in the present study described an embodiment with their prosthesis - it was part "of them", and they felt whole and more fully themselves. However, this embodiment was a fluctuating and fragile experience. Contradictions in accounts and in behaviour suggest that prostheses may sometimes have been used more as a tool for managing social and psychological difficulties than as truly embodied. This corresponds with Murray's (2004) distinction between those with a close emotional bond with their limb prosthesis and those who use it only as a social or functional tool, and suggests that those with a facial prosthesis may experience elements of both these states to different extents and in different settings.

The experience of having a facial prosthesis was positive for all participants. However, several themes suggest a dissonance in the experience of living with a facial prosthesis. First, living with a facial prosthesis cannot be separated from the context of changed facial appearance. Second, prostheses were highly valued yet there was a limit to the psychological benefits it brought. Third, there was a fragility in participants' descriptions of embodiment of their prosthesis. Other qualitative work focusing on the phenomenology of limb prosthesis use have identified similar tensions. Murray and Forshaw's (2013) meta-synthesis found an emotional ambivalence towards the prosthesis, in which participants valued the benefits of their prosthesis whilst also grieving for the loss of their limb. A qualitative study with early-adjusting lower-limb prosthesis users explored this ambivalence further and reported experiences of feeling “in-between” old and new lives, and oscillation between “experiences of victory and defeat” as a result of having a prosthesis (Norlyk, Martinsen, Hall, & Haahr, 2016, pp. 7). The present study extends these findings to facial prosthesis users, and suggests that these experiences may continue beyond initial adjustment.

A focus on positive adjustment was not an intended aim of this research, however these characteristics in the final sample have allowed an exploration of these factors. Humour was a common and effective strategy for socially integrating the changed facial appearance and the prosthesis. Saradjian, Thompson, and Datta’s (2008) study of positive coping in upper-limb prosthesis users corroborated the finding that humour regarding prostheses could enable social inclusion and normalise the prosthesis in social situations. In this way, humour is used as a coping strategy for managing others’ reactions, and the participants in the present study suggested that humour played dual social and psychological roles – putting others at ease as well as boosting self-esteem and belonging in social situations. Oaksford, Frude, and Cuddihy’s (2005) study with lower-limb amputees also identified humour as an essential ingredient for coping and suggested that the use of humour may increase in longer term adjustment.

Themes of optimism and stoicism were common for participants in this study, and seemed to be more dispositional than learned strategies. Several studies have identified optimism as a key feature of positive adjustment to changed facial appearance (e.g., Allison, Guichard, & Gilain, 2000; Furness, Garrud, & Swift, 2006; Egan et al., 2011) The Appearance Research Collaboration’s framework of adjustment to unusual appearance includes optimism as a cognitive factor which moderates clinical and demographic variables to account for positive adjustment following HNC (Clarke, Newell, Thompson, Harcourt, & Lindenmeyer, 2013). Stoicism as a coping strategy is less well researched, however Thompson and Broom (2009, pp.178) identified traits of “dogged determination” in people who coped positively with a visible difference, which may be a similar construct to the stoicism reported here.

Much previous research has explored the role of downward social comparison in maintaining self-esteem for stigmatised groups (Festinger, 1954; Crocker & Major, 1989). In this sample, participants found benefits in remembering that their experiences, although difficult, were not as bad as they could have been, and they gave specific examples of other people who were “worse off”. This supports Taylor, Wood and Lichtman’s (1983) concept of downward social comparison as a cognitive strategy for evaluating a difficult situation in a more positive light. Many other qualitative studies of both visible difference and prosthesis use have linked downward social comparison and positive adjustment (e.g. Egan et al., 2011; Gallagher & MacLachlan, 2000).

Methodological limitations

To the researcher’s knowledge this is the first qualitative study to examine the unique experience of individuals living with a facial prosthesis. The use of a qualitative IPA methodology extended previous research by enabling a richer, more complete and contextualised understanding of the experience that could not be gained solely through quantitative studies. The findings can contribute to interventions by demonstrating factors associated with positive adjustment, particularly the potential for peer or online support interventions. Future avenues for research have been opened, particularly regarding those with negative adjustment that was not covered in this study.

The recruitment strategy employed in this study resulted in a sample of seven participants. While this is at the lower end of recruitment for IPA studies, Smith et al. (2009) contends that the quality of data gathered and the depth of understanding gained is more important in IPA than the number of participants; indeed, in-depth exploration of fewer participants’ experiences is preferable to a superficial understanding of many. In this study, the use of an additional photo-elicitation task brought greater depth and clarity of understanding to participants’ accounts in the substantive interview. There are numerous examples of IPA studies using smaller samples, including some single case studies (e.g. Smith, 1999; Knudson & Coyle, 2002; Bramley & Eatough, 2005; Smith & Osborn, 2007; Shinebourne & Smith, 2008).

Heterogeneity was evident in the sample in terms of type of prosthesis, aetiology, gender and duration of wear of prosthesis. Heterogeneity in an IPA sample can be problematic, since the overall themes may not be representative of the phenomenon in question and the credibility of the findings may be compromised (Smith, Flowers, & Larkin, 2009). In particular, there was notable difference in the age and life-stage of participants who acquired their prosthesis through a traumatic accident and those who acquired it through cancer. As discussed, this division in the sample inevitably led to differences in the experiences of the two groups in relation to their prosthesis, with the trauma group expressing more regret for the changed trajectory of their lives, and the cancer group expressing more fear for the future. Future research would be needed to explore the differences in these experiences in more depth. Despite these discrepancies, the sample was fortuitously homogenous in terms of well-being. All participants scored in the mild range on measures of anxiety and depression, and reported positive adjustment to living with their prosthesis. The heterogeneity of the sample was also tempered by the consistent themes that were elicited across all accounts regardless of demographic and clinical differences within the sample. The sub-theme "the added burden of cancer", was evidently only applicable to the four participants who had cancer, however the strength of this theme in their accounts when compared to the non-cancer accounts was interesting. All remaining themes were consistent across all accounts.

The process of adjustment over time to acquiring and living with a prosthesis was not explicitly addressed by the interview schedule, which limits the conclusions that can be drawn about changes in experience over time. Due to the limited size of the target population, duration of prosthesis wear was not specified in the inclusion criteria and so the interview schedule was created to avoid assumptions based on stage of adjustment. The eventual sample in this study was made up of older people who had used a prosthesis for some years. The longer duration of wear in this sample strengthened the accounts in terms of the phenomenology of long-term adjustment; these participants had had more opportunity to reflect on the meaning of their prosthesis and could remember and conceptualise their experience over a range of settings. The lack of consideration in the interview schedule of experiences over time meant that the journey which brought them to their current experience was not fully explored. Even if this had been explored, however, the actual experience of going through the earlier stages of adjustment would have been harder to access in retrospect for this sample. Participants did spontaneously talk about the changes in their experience over time and how the journey impacted on their current experience. The themes drawn from their accounts (Figure 2) illustrate what was important to participants at different times. Theme 1 discusses the experience of acquiring a change to facial appearance, theme 2 considers what it was like to live with changed facial appearance, and theme 3 concerned the difference made by having a prosthesis. Future research would benefit from considering the phenomenology of this journey in more depth.

Future research

Many of the findings from this study have been compared to findings from studies on limb-prostheses. There appears to be notable overlap in the experiences, however more research specifically about facial prostheses is needed to corroborate this study and test the links with limb-prosthesis research. The findings from this study particularly call for more research exploring different stages and levels of adjustment. This study focused on continuing, positive adjustment, so studies on early adjustment and factors related to negative adjustment are needed. Future research will therefore need to employ more targeted recruitment of these specific populations. Given the limit to the benefits of having a facial prosthesis and the positive adjustment in this sample, future research could explore participants' expectations for their prosthesis before and during early adjustment. Ostler, Ellis-Hill, and Donovan-Hall's (2014) qualitative study with lower-limb amputees found that expectations for the prosthesis were uninformed and unclear, and that the main expectation was a return to full normalcy. It remains unclear if these findings extend to people with facial prostheses. Osseointegrated prostheses were preferred to adhesive prosthesis by participants in this study, so research exploring advances in prosthetic materials should seek to collaborate with patients regarding the acceptability of proposed materials.

Clinical implications

The findings from this study should be used to train staff working with prosthetic users. The participants in this study had a positive experience of prosthesis use, tempered by some limitations. They also described a number of strategies they have used as part of their positive adjustment. In light of this, staff can encourage future patients that others in a similar position have adjusted very well and found value in their prosthesis use, whilst also keeping expectations realistic and giving an accurate picture of the difficulties that the prosthesis may present. Common strategies, such as the use of humour or positive comparisons, could also be discussed by staff with their patients.

The participants in this study highly valued the consistent support offered by their prosthetic clinicians, as discussed in theme 4.4. Clinicians who took a collaborative approach by involving their patient in decisions and actively listening to their preferences, hopes and concerns regarding their prosthesis were especially valued. Some participants found the process of having their prosthesis fitted very uncomfortable, while some found it quite enjoyable. So, individual needs should be identified without assumption, and provisions made to minimise discomfort. Participants alluded to positive experiences with the care team contributing to their motivation to attend regularly. Prosthetists and other clinicians could benefit from being aware of psychosocial indicators of negative adjustment, for example evidence of social avoidance, self-shaming comments or lack of self-care and links between prosthetic and psychology services should be established to provide timely support to these patients.

Supportive relationships in which participants felt accepted and valued were a central aspect to positive adjustment in this sample (theme 4.4). Several participants reported that they would like to be able to talk to others with a facial prosthesis and expressed a warm curiosity about others' experiences. Peer support groups can provide these opportunities in order to maximise positive adjustment. Peer support has been implicated as helpful for people with unusual facial appearance (e.g. Clarke, 1999) and those with limb prostheses (e.g. Biddiss & Tom, 2007); any such groups for facial prosthesis users should be evaluated to establish their helpfulness. One participant in this study had provided peer support to others with a facial prosthesis and reported this to be mutually helpful; this informal, one-to-one peer support could also benefit from further exploration. The population of people using a facial prosthesis is fairly small and can be geographically dispersed, which would make support groups practically difficult. Online peer support has been found to be beneficial for head and neck cancer patients (Al Gtewi, Owens, & Baker, in press) and may also be useful for facial prosthesis users. Two participants in this study reported using online platforms to engage with SUI initiatives, so an online support group may be more feasible for some than meeting in person.

Conclusion

Losing part of the face had a profound impact on the participants in this study, and altered facial appearance led to considerable felt and enacted stigma. Having a facial prosthesis restored facial appearance and countered the negative social and self-identity challenges associated with changed facial appearance. Humour, optimism, stoicism and acceptance in valued relationships were characteristics most strongly associated with the positive adjustment of this group of participants. However, there is a limit to the benefits of a facial prosthesis – participants experienced a dissonance in their experiences as the prosthesis could only partially restore the previous, normal self. The prosthesis can act as a symbol of hope and healing, and at the same time as a reminder of the distressing experiences of altered appearance, disease or trauma. Peer support and close links between prosthesis and psychology services are recommended and further research is needed to explore the earlier experiences of adjustment and negative adjustment to facial prosthesis.

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Section 3

Appendices

Appendices List

Appendix A: Literature review search terms

(Qualitative AND ("grounded theory" OR "discourse analysis" OR "interpretative phenomenological analysis" OR "interview*" OR "focus group*" OR “case stud*” OR “mixed method*” OR "thematic analysis" OR ethnograph* OR “narrative analysis” OR phenomenolog* OR psychological OR psychosocial OR “content analysis”))

AND

(Disfigure* OR deform* OR differen* OR surgery OR trauma OR resect*)

AND

(Face OR facial OR head OR craniofacial OR oral OR mouth OR orofacial OR orbitofacial OR nasal OR nose)

AND

(Cancer* OR tumour OR tumor OR neoplasm OR carcinoma OR malignan*)

Appendix B: Quality appraisal tool for qualitative studies

This checklist is based on:

1) Spencer, L., Ritchie, J., Lewis, J., & Dillon, L. (2003). *Quality in qualitative evaluation: a framework for assessing research evidence.* London: National Centre for Social Research/Cabinet Office.

Available from:
http://dera.ioe.ac.uk/21069/2/a-quality-framework-tcm6-38740.pdf

2) Critical Appraisal Skills Programme (CASP). (2013). *10 Questions to help you make sense of qualitative research.*

Available from:
http://media.wix.com/ugd/dded87_29c5b002d99342f788c6ac670e49f274.pdf

Screening Questions

1. Was there a clear statement of the aims of the research?	Clear ☐ Unclear ☐ Not sure ☐ Comment:
2. Is a qualitative methodology appropriate?	Clear ☐ Unclear ☐ Not sure ☐ Comment:
Is it worth continuing?	Yes ☐ If yes, continue to next section. No ☐ If no, why not?

Research design:

3. Was the design appropriate to address the research aims? - is the design justified? - are any changes justified?	Appropriate ☐ Inappropriate ☐ Unsure ☐ Comment:

Sampling:

4. Was the recruitment strategy appropriate?
– how were participants selected?
– explanation for suitability of participants recruited?
- is the sample representative?
- Did any participants not take part

Appropriate ☐

Inappropriate ☐

Unsure ☐

Comment:

Data collection:

5. Were the data collected in a way that addressed the research
issue?
– Are all aspects of data collection clear, explicit and theoretically justified? Think about: setting, means, procedure (including interview schedule), modifications to methodology, form of data, saturation of data.

Adequate ☐
Inadequate ☐
Not sure ☐
Comment:

Reflexivity and validity:

6. Has the relationship between researcher and participants been adequately considered?
– Critical examination of researcher' role, bias and influence on data throughout the entire research process, including any changes?

Defensible ☐
Not defensible ☐
Unsure ☐
Comment:

6.1 Is the context clearly described?
- Clear definition of participants and settings, observations from a variety of circumstances, consideration of context bias.

Clear ☐
Unclear ☐
Not sure ☐
Comment:

6.2 Were the methods reliable?
- Multiple methods of data collection, triangulation?
- Do the methods do what they claimed to investigate?

Defensible ☐
Not defensible ☐
Unsure ☐
Comment:

Ethical Issues:

7. Have ethical issues been taken into consideration?
– Enough detail to convey that ethical standards have been maintained, discussion of issues raided by the research, evidence of Ethics Committee approval?

Defensible ☐

Not defensible ☐

Unsure ☐

Comment:

Data Analysis:

8. Was the data analysis sufficiently rigorous?
– In-depth description of analysis process, clear desctiption of how themes are derived from data, explanation of why selected data how been chosen for presentation, sufficient data presented to verify themes, are contradictory data accounted for?

Adequate ☐
Inadequate ☐
Not sure ☐
Comment:

8.1 Are the data 'rich'?
- Are the contexts of the data clear? Have different viewpoints been explored? Sufficient demonstration of detail and depth? Comparisons between different data sets?

Adequate ☐
Inadequate ☐
Not sure ☐
Comment:

Findings:
9. How does the evidence support the findings?
– Findings should be explicit, coherent and credible (triangulation, independent analysts, respondent validation). Findings should be discussed in relation to evidence. Are interpretations justified and clearly argued? Are alternative explanations offered?

Defensible ☐

Not defensible ☐

Unsure ☐

Comment:

Value of the research:

10. How valuable is the research?
– Do findings fit with extant literature? Consideration of current practice and policy? Further research identified? Has the research question been answered? How do the findings fit with existing knowledge?

Defensible ☐

Not defensible ☐

Unsure ☐

Comment:

Appendix C: Summary of quality appraisal

	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. Were the data collected in a way that addressed the research issue?	6. Has the relationship between researcher and participants been adequately considered?	6.1. Is the context clearly described?	6.2. Were the methods reliable?	7. Have ethical issues been taken into consideration?	8. Was the data analysis sufficiently rigorous?	8.1. Are the data 'rich'?	9. How does the evidence support the findings?	10. How valuable is the research?	QUALITY
Furness et al. (2006)	✓	✓	✓ GT to explain experience	✓wide range of recruitment avenues described	✓description on modifying data collection to suit participant needs	Not defensible	✓adequate description and rationale for heterogeneity of data	✓Focus groups, interviews and surveys. Independent data audit	Not defensible	✓step by step description given, sufficient raw data included	✓good description of contexts from diverse viewpoints	✓ findings explicit, fits model, could be more coherent	✓discussion of implications for practice, further research	Satisfactory
Konradsen et al. (2009)	✓	✓	✓Use of GT to generate a model	✓homogenous sample of participants	✓Individual interviews and recorded interactions were analysed until saturation	Not defensible	✓	✓ Research team discussed findings, original data checked	✓Good description of how ethical issues were addressed	✓Step by step description given, sufficient raw data included	✓context given to data and themes, contrasting views expressed	✓	✓good discussion of clinical and theory implications	Key paper

Speraw (2009)	✓	✓	✓case study to explore the concept of personhood	✓case study drawn from a larger sample	✓good account of data collection and detail of interview	✓field notes were taken after interview and incorporated into analysis	✓good detail of the context around the case	✓interview continued until saturation	✓detailed description of ethical issues at each stage	✓good description of methods and use of group to verify coding	✓ rich raw data excerpts, contextual details	✓findings related to range of theories	Unsure – n=1 means no generalisability	Satisfactory
Turpin et al. (2009)	✓	✓aim to explore personal meaning of experience	✓rationale provided for design	Unsure - insufficient detail of how the 11 participants were recruited	✓	Not defensible	✓useful context re: participants' backgrounds	✓interviews and repertory grids used	Not defensible	✓	✓	✓	✓Theory and clinical implications considered	Key paper
Van Doorne et al. (1994)	✓	✓aim to understand ppt experience	✓design suitable for aims	Unsure - limited detail on how final sample was selected	Partially defined – insufficient detail on interviews	Not defensible	Unclear	Inadequate - no description of triangulation	Not defensible	Inadequate - no description of analytical process	Inadequate - insufficient depth of reporting	Inadequate - almost no comparison to literature	Unsure – minimal mention of clinical implications	Questionable
Bonanno & Choi (2010)	✓	✓outlined and specific to interactions with secondary groups	✓Qualitative methods appropriate given under-theorised area	Unsure - limited detail of strategy	✓sufficient detail provided on methodology	Not defensible	Unclear - little detail	Inadequate - insufficient detail provided on procedure of GT	Not defensible	Unsure - little detail on how themes and patterns have been identified	✓	✓good discussion of interpretation and findings in relation to literature	✓	Questionable

Konradsen et al. 2012.	✓	✓	✓	✓follow-up of previous study, in order to explore adjustment	✓	Not defensible	✓good background of previous study provided	✓sufficient detail of interview procedure	✓thorough account	✓step by step description given, sufficient raw data included	✓context of data well described	✓	✓	Satisfactory
Bonano & Esmaeli (2012)	✓	✓aim to explain experience of interaction	✓semi-structured interviews	✓theoretical sampling in line with GT until saturation	✓	Not defensible	✓	✓	Not defensible	✓description of analysis process given, sufficient raw data	✓	Unsure - discussion in relation to literature is limited	✓	Satisfactory
McGarvey et al. (2014)	✓	✓	Unsure - no specific qualitative methodology named	✓	Partially defined - some interviews very short (3 minutes)	Not defensible	✓	Unsure - median length of interview was 10 minutes - short	✓	✓adequate description of analysis, reviewed by 2nd researcher	Unsure- limited data collected, but various views dicussed	✓	✓explicit discussion of clinical implications	Satisfactory
Costa et al. (2014)	✓	✓seeking to understand experience	✓	✓sample limited to population covered by aims	✓semi-structured interview focusing on aspects of facial changed facial appearance	✓Researchers background considered as well as wider cultural and political issues	✓sufficient detail of background	✓good detail provided which ensures replicability	✓	✓thorough account of GT, raw data included	✓	✓	✓linking to literature and clinical implications	Satisfactory

Henry et al. (2014)	✓	✓aim to explore lived experience	✓good use of interviews using IPA	✓use of maximum variation sampling	✓good description of interview methodology	✓helpful account of reflexive factors provided	✓	✓	Unsure - ethics approval gained but no further description	✓	✓	✓	✓	Key Paper
Nayak et al. (2016)	✓ - in abstract only though	✓mixed methods approach used	Unsure - semi-structured interviews chosen but rationale for design not stated	Unsure - little detail of purposive sampling, no rationale for inclusion of women only	Partially defined - no detail provided beyond "semi-structured interview on body image"	Not defensible	Not defensible - characteristics of participants not described	Unsure - triangulation is mentioned but no detail is provided	✓	Unsure - some information about use of Colaizzi process, but not detailed enough	Inadequate	Inadequate - not in clear English, limited critiqueof literature	Inadequate	Fatal Flaw
Lee et al. (2016)	✓	✓	✓semi-structured interviews to identify patient experience	✓purposive sampling of eligible participants at a large cancer centre	✓useful inclusion of interview schedule, details of modifications	Not defensible	✓good detail of participant characteristics	Unsure - not specified if triangulation/ multiple coders were used	✓	Unsure - details provided of analysis process but no raw data included	Unsure - some rich description of data, but raw data not included	✓coherent and relevant findings and evidence discussed	✓contributing towards an outcome measure	Satisfactory

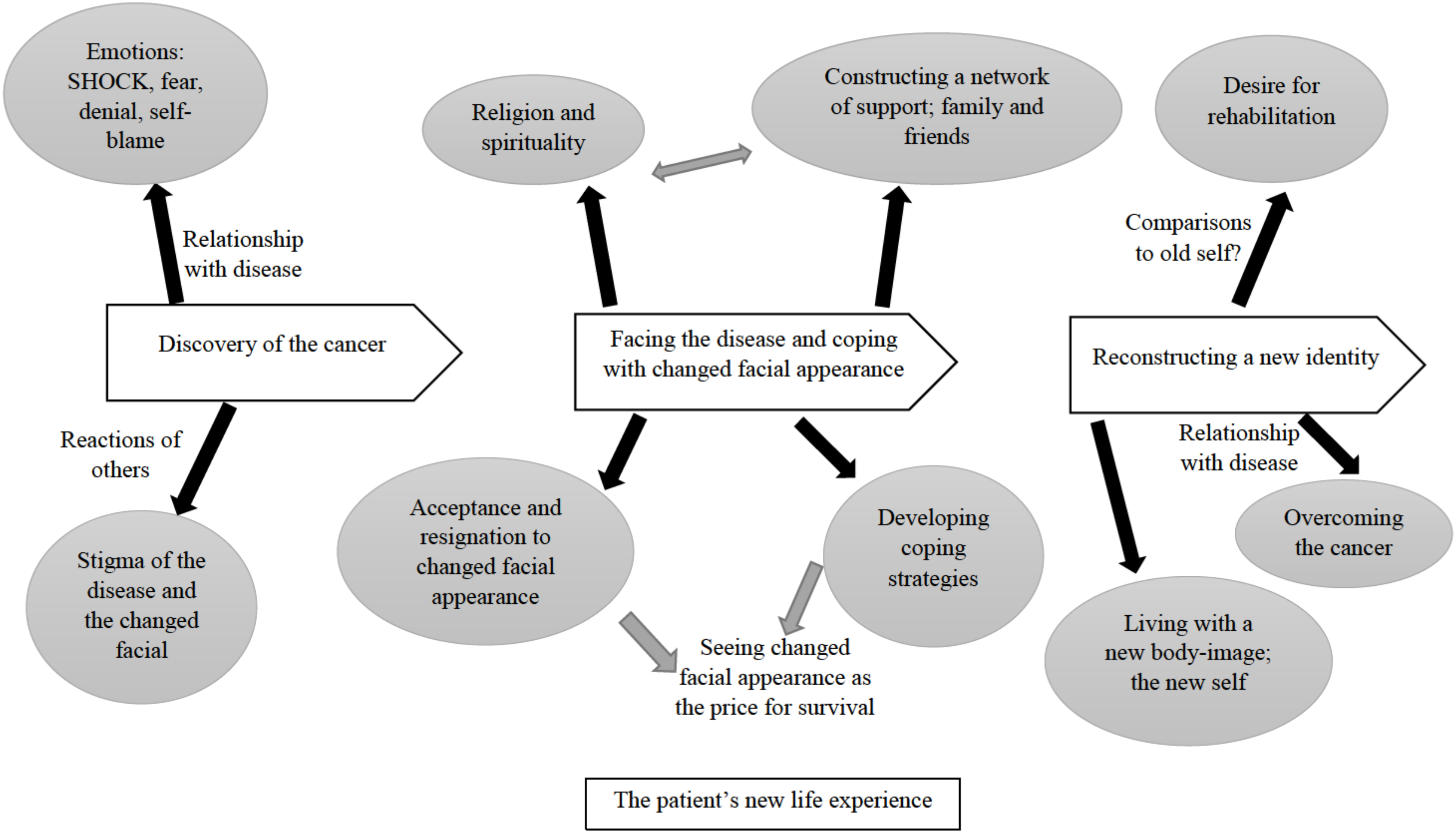
Appendix D: Summary table of second and third order constructs

Category	2nd order construct	Summary definition	Papers included
Changes to sense of self	Ruptured sense of self	Sense of self as an individual person with a unique role in the world is damaged by the changed facial appearance, and there is a gradual process of rebuilding a new self as congruent with previous identity, as a survivor, and developing new strengths	11, 4
	Destruction of valued roles		4
	Reconstructing own identity		10, 11, 4
	Striving to develop as a person		11, 10
	Wanting a better future		10, 11
	Adjustment is a gradual process		10, 5
	Striving to regain sense of self		11, 4
	Valued new identity as a survivor		4, 3
Self to self relating	Negative body image	View of altered self as negative and incongruent, leading to more awareness and attempts at avoidance of feelings about appearance	9, 4, 11
	Anger and shame towards changed facial appearance		3
	Noticing own emotions and responses more		7
	Avoiding own emotions and thoughts		4
	I'm unattractive, ugly		4, 11, 9
	I'm inadequate		11, 4
	Shock in looking at self		11, 10
	I'm different		9, 11,
	I'm not me		4
The self in the world	Being conspicuous, garnering attention	The feeling of drawing a lot of attention by virtue of being different	11, 4, 6, 7, 8
Others' reactions	Making others uncomfortable	Others’ negative reactions and the amount of attention given to the changed facial appearance in interactions plays an important role	3, 10, 11, 6, 8
	Provoking pity, sadness and sympathy		11, 10

	Provoking shock and disgust		11, 10
	Stigma		10, 8,6
	Provoking staring, comments and questions		6, 8, 11,
	Being avoided		4, 3, 10
	I'm inferior compared to society's standards		7, 10, 8, 6, 11
	Feeling judged by others		11,5
Acceptance by others	Interactional integration of changed facial appearance	Changed facial appearance becomes integrated into social interactions when the individual and others break the silence; it becomes more normal. The closeness of the relationship with others impacts on how interactions are experienced.	11
	Close relationships, acquaintances, strangers		4
Relationship with the disease	Emotional journey - Shock, denial, fear, relief, worry	Individuals go through a wide range of emotions and practical problems over the course of the disease; the ongoing changed facial appearance often serves as a reminder of the disease.	10, 13,
	Changed facial appearance as a reminder of disease		11,
	Practical problems		13
	Attempts to reduce likelihood of disease		13
Survival is paramount	Changed facial appearance is a luxury issue	Surviving is held as more important than being disfigured.	2, 5, 12, 10
	Changed facial appearance is the trade-off for survival		10, 11, 13,
Coping	Social avoidance	Individuals' attempts to cope with changed facial appearance and appear "normal" by avoiding social situations and concealing the changed facial appearance. Personality, age, gender, life events and religion all play a role in how people try to cope.	9, 7, 11, 10
	Concealment		4, 10, 11, 13, 9
	Role of age		12, 13, 4
	Role of gender		9, 11
	Role of personality		11, 1
	Role of past and concurrent events		11, 1,
	Role of spirituality and religion		10

The care team	Changed facial appearance is silenced	The role of the care team in managing changed facial appearance is important to individuals, especially being treated in a humane way which acknowledges the changed facial appearance but does not discriminate against it.	2, 3
	Being treated as human		
	How changed facial appearance is dealt with is important		13, 11, 3

Appendix E: Example of a conceptual map (from Costa et al., 2014)



Appendix F: Recruitment letter

The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training
& consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TN UK

Date:……………………….

Dear …….

We are conducting some research about what it is like to live with a facial prosthesis. This research aims to contribute towards the provision of better support and services for people who use a facial prosthesis in the future.

We are conducting this research in collaboration with The University of Sheffield. The lead researcher will be Iona Shepherd, a Clinical Psychologist-in-training at the university.

If you would be interested in taking part in this research, please read the enclosed information sheet to find out more. If you decide that you would be willing to participate in the research, I'd be grateful if you could complete the enclosed forms and return them to Iona in the freepost envelope provided.

Thank you for considering participating in the research.

Yours sincerely,

…………(Clinician's name)………………

…………(Role)…………………………………

In collaboration with:

Iona Shepherd

Trainee Clinical Psychologist, the University of Sheffield

Appendix G: Participant information sheet and photo-elicitation instructions

The University Of Sheffield.

Department Of Psychology.

Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Sheffield S10 2TN UK

Information Sheet

Research Project Title: The Experience of Facial Prosthesis.

You are being invited to take part in a research project. Before you decide it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and discuss it with others if you wish. Feel free to call the researcher on the number at the end if there is anything that is not clear or if you would like more information.

The researcher's name is Iona Shepherd. She is training as a Clinical Psychologist at the University of Sheffield, and she is interested in finding out about your experiences of using a facial prosthesis.

What is the project's purpose?

The study intends to understand what life is like for people who have a facial prosthesis. As well as informing our understanding of the experience of living with a facial prosthesis, it is hoped that the information gathered might give professionals information as to how to provide better support for people.

Why have I been chosen?

You have been chosen to take part because you have received prosthetic treatment through [Sheffield Teaching Hospitals NHS Foundation Trust *or* The Rotherham NHS Foundation Trust]. We have sent this information out to all patients who have had prosthetic treatment at these clinics.

You are eligible to participate in this study if you are over the age of 18 and are a fluent English speaker.

Do I have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will need to sign the consent form also included with this letter. You can withdraw from the research without it affecting your treatment in any way. Iona will not ask you why you are withdrawing and will respect your decision. After the interviews, if you decide you no longer want your data to be used you will have four weeks to withdraw it from the study. After that time the data will have been analysed.

What will happen to me if I take part?

The first part of the research is a brief survey. The survey is included with this letter and contains a short questionnaire. This should take about no more than 15 minutes to complete. The survey will also include a question asking you if you want to take part in the second part of the research. You will need to return the survey using the Freepost envelope provided.

The second part of the research consists of two meetings with Iona. If you indicate on the survey that you're happy to be contacted, Iona will telephone you to arrange a meeting. The first meeting will last no more than 30 minutes and will be an opportunity for Iona to explain the study in more detail and answer any questions. Following this meeting you will be asked to take photographs over the following weeks that capture or represent how you get along with using your facial prosthesis. You do not have to take photos if you'd prefer not to and you can still take part in the study if you don't take any. If you do choose to take photos they can be of anything that will act as a reminder of your experience of using your facial prosthesis (i.e. you do not have to take photos of yourself, although you may if you wish. The photos could be of objects or other reminders of your daily experience).

The second interview will be two-four weeks later and will last about 60-90 minutes, plus breaks if you want. Iona may telephone you in-between the two meetings to remind you of the task, if you agree to this. At the second meeting, Iona has a number of questions she will ask you but she is interested in hearing about what's important to you. What you share with Iona is up to you – if you don't want to answer a question, you will not be required to do so.

Interviews can take place at your home or an alternative setting, such as at the University of Sheffield, if you prefer. The interviews will need to take place in a quiet and private place so that you can feel comfortable talking about your experiences. You may have someone with you during the interview if you want, however the research is interested in your views so all answers need to come from you alone. Iona will take audio recordings during the interviews so that she can get an accurate record of your point of view.

What are the possible disadvantages and risks of taking part?

Sometimes talking about their experiences can be distressing for people. If you get upset Iona will ask you if you want to continue. If you are happy to continue, you may take some time out first. If Iona becomes concerned about your well-being, she may advise you to contact your GP and notify the collaborating hospital.

What are the possible benefits of taking part?

Whilst there are no immediate benefits for you participating in the research, some people find it helpful to talk about their experiences. It is also hoped that the results of the research will help professionals to provide better services and support, which may help other users of a facial prosthesis.

Will I be recorded, and how will the recorded material be used?

The audio recording of your interview and your photographs will be used for analysis. Parts of the interview will be used anonymously (without your name) for illustration in reports (e.g. thesis and journal article/s) and presentations (e.g. to support groups/conferences/teaching of healthcare professionals). No other use will be made of them without your written permission, and no one outside the project will be allowed access to the original recordings or photographs. The recordings themselves will be destroyed after Iona has completed her degree. The anonymous (nameless) transcripts will be kept. Your photographs will be downloaded onto an encrypted computer and saved under a code number (not your name). Iona will refer to the photos when analysing the interviews. The photographs will be deleted at the end of the project, and will not be used in any reports, publications or presentations.

What if something goes wrong?

If you are unhappy about something that has occurred in the research, it is important that you inform The University of Sheffield. In the first instance, please address any complaints to the academic supervisor: Dr Andrew Thompson, Reader in Clinical Psychology, at the Clinical Psychology Unit, Department of Psychology, the University of Sheffield, Western Bank, Sheffield, S10 2TN, a.r.thompson@sheffield.ac.uk.

Will my taking part in this project be kept confidential?

All the information that is collected about you during the course of the research will be kept strictly confidential. As previously described select quotes from your interview will be used to support the findings of the study. However this will not contain any information that could be used to identify you and you will not be named in any reports or publications.

What happens to the results of the research project?

Iona hopes to share the findings with professionals working with people who use a facial prosthesis. The findings will also be published in an academic journal and be presented at conferences.

Who is organising and funding the research project?

The research project is being organised and conducted by the Department of Psychology, at The University of Sheffield, in collaboration with Sheffield Teaching Hospitals NHS Foundation Trust and The Rotherham NHS Foundation Trust.

Who has ethically reviewed the project?

This project has been ethically approved by proportionate review through the NHS Integrated Research Application System.

Contact for further information

For further information or if you have any questions about the project, please contact the Research Administrator at the Clinical Psychology Unit on 0114 222 6576 and ask to leave a message for Iona Shepherd. The Research Administrator cannot answer your question themselves but will relay your message to Iona, who will then call you back at the earliest opportunity.

If you are willing to take part, please sign the enclosed consent form and questionnaires and return them using the freepost envelope provided.

Thank you for taking the time to read this information.

Taking photos to prepare for the interview - Instructions

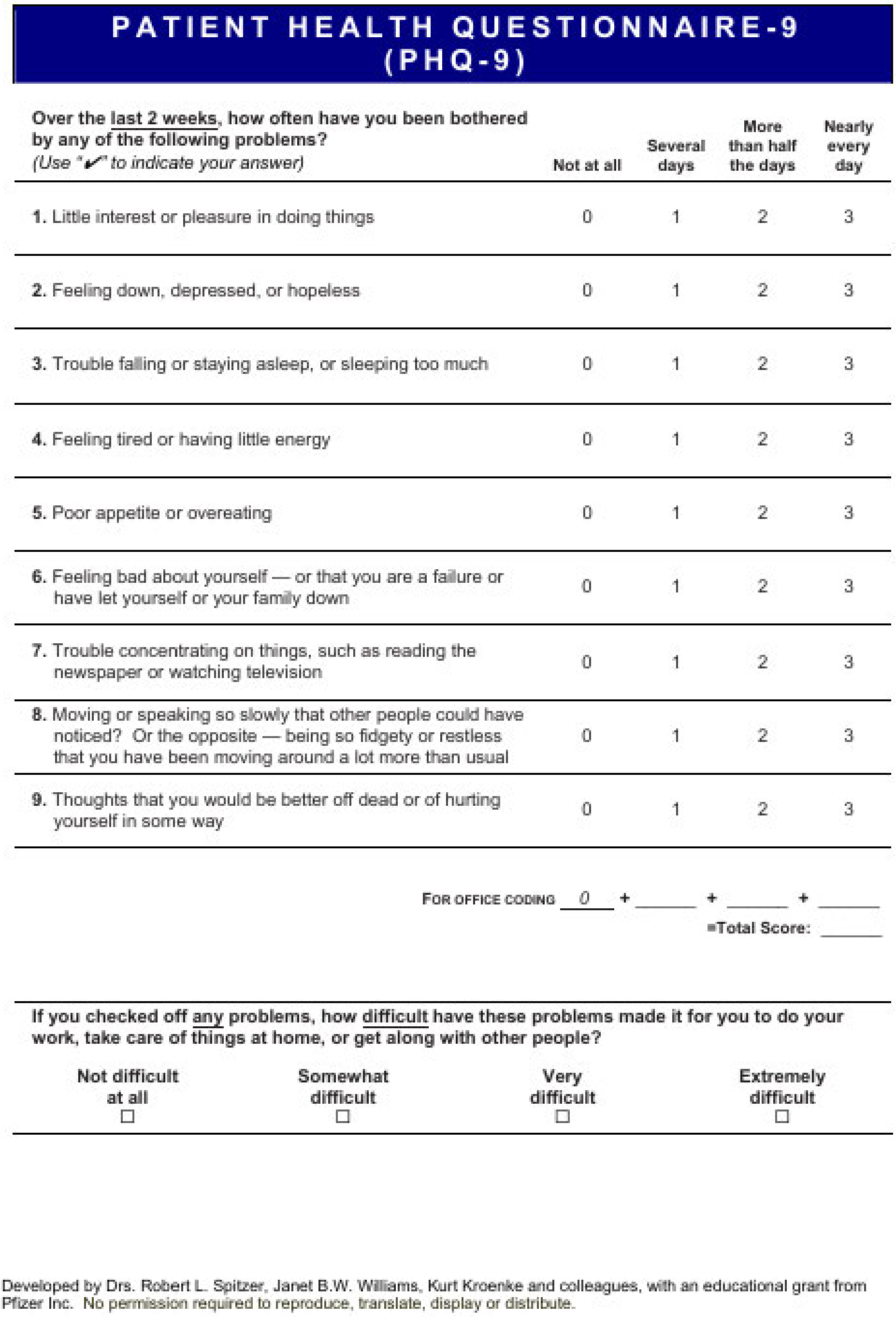
As part of the research I am asking people if they could take some photographs to help show what it is like to have a facial prosthesis. These instructions will remind you of what to do for the photo task.

- We would like you to take photos of anything relating to your experience of having a facial prosthesis. We want to understand the things that are important to you - this might be about how you are feeling, the thoughts you have, what it's like with other people or any other experiences you think are important.
- The photos can be of anything you like, as long as they are related to what it is like to have a facial prosthesis. You do **not** have to take photos of yourself or your prosthesis, although you can if you want.
- An example might be that you meet a friend and have a conversation about your prosthesis. You could photograph the person, the place you met, an object that reminds you of them. Anything at all that is a reminder for you about what was important about that experience.
- If you are using your own camera, Iona will bring a computer to the next meeting so that we can look at the photos together on a larger screen. If you are using a disposable camera, please post it back to Iona using the freepost envelope provided so that she can develop the photos before the interview. Iona will give you a call to remind you about this. At the interview, we will talk about what the pictures mean to you.
- Don't worry if you don't manage to take any photos. We would still like to talk with you at the second meeting about your experiences of facial prosthesis. There is no pressure for the photos to be "artistic" or for you to go to any inconvenience to take photos – we are interested in your normal, everyday experience.

If you have any questions or concerns about any part of this process please contact the Research Administrator at the Clinical Psychology Unit on 0114 2226650 and leave a message for Iona Shepherd. The Research Administrator cannot answer your questions but messages will be passed on to Iona, who will get back to you as soon as possible.

Thank you again for taking part in the research!

Appendix H: Blank PHQ-9 and GAD-7 measures



PATIENT HEALTH QUESTIONNAIRE-9 (PHQ-9)

Over the <u>last 2 weeks</u>, how often have you been bothered by any of the following problems? *(Use "✓" to indicate your answer)*	**Not at all**	**Several days**	**More than half the days**	**Nearly every day**
1. Little interest or pleasure in doing things	0	1	2	3
2. Feeling down, depressed, or hopeless	0	1	2	3
3. Trouble falling or staying asleep, or sleeping too much	0	1	2	3
4. Feeling tired or having little energy	0	1	2	3
5. Poor appetite or overeating	0	1	2	3
6. Feeling bad about yourself — or that you are a failure or have let yourself or your family down	0	1	2	3
7. Trouble concentrating on things, such as reading the newspaper or watching television	0	1	2	3
8. Moving or speaking so slowly that other people could have noticed? Or the opposite — being so fidgety or restless that you have been moving around a lot more than usual	0	1	2	3
9. Thoughts that you would be better off dead or of hurting yourself in some way	0	1	2	3

FOR OFFICE CODING 0 + ______ + ______ + ______

=Total Score: ______

If you checked off <u>any</u> problems, how <u>difficult</u> have these problems made it for you to do your work, take care of things at home, or get along with other people?

Not difficult at all	**Somewhat difficult**	**Very difficult**	**Extremely difficult**
☐	☐	☐	☐

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

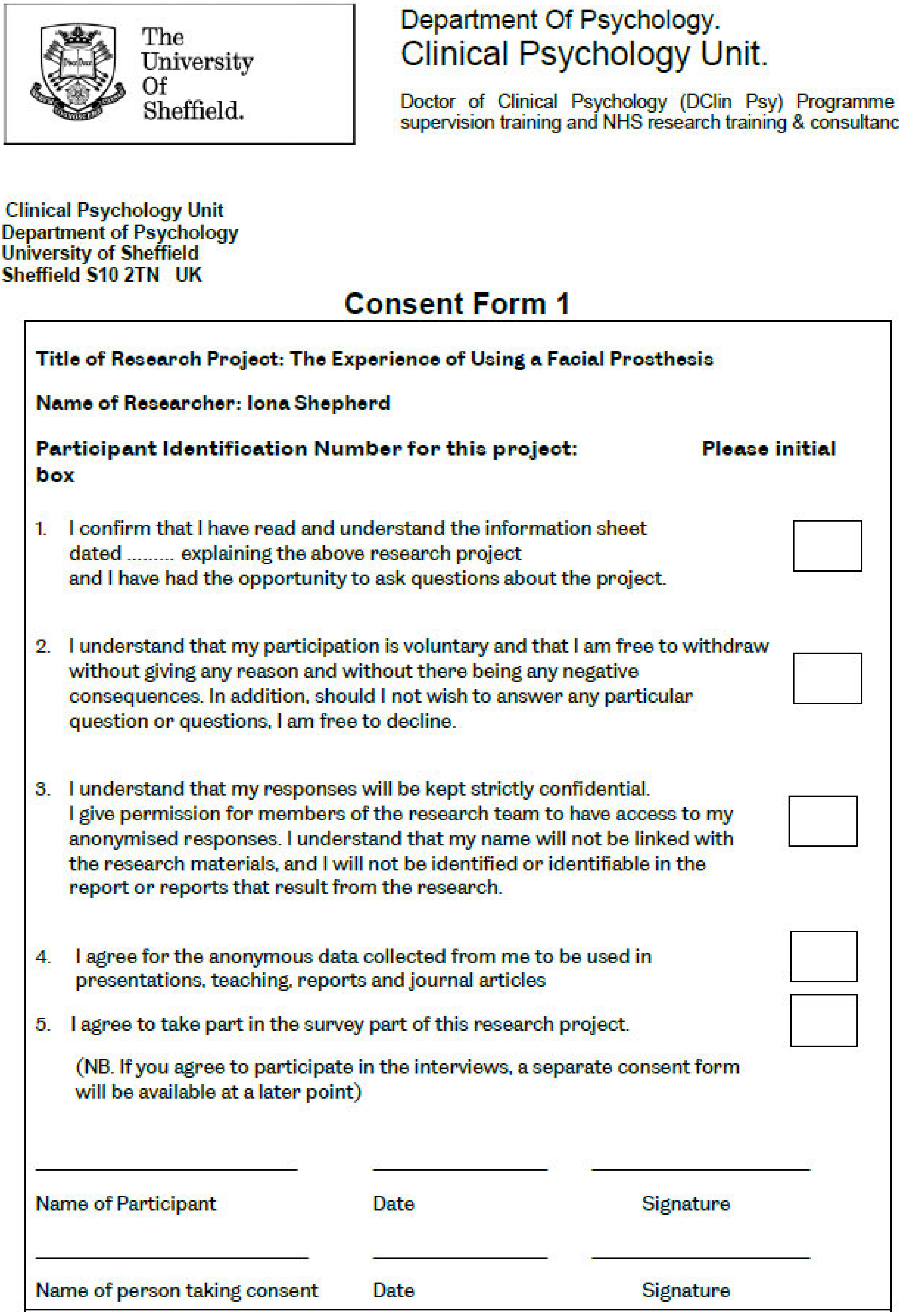
GAD-7

Over the <u>last 2 weeks</u>, how often have you been bothered by the following problems? *(Use "✔" to indicate your answer)*	Not at all	Several days	More than half the days	Nearly every day
1. Feeling nervous, anxious or on edge	0	1	2	3
2. Not being able to stop or control worrying	0	1	2	3
3. Worrying too much about different things	0	1	2	3
4. Trouble relaxing	0	1	2	3
5. Being so restless that it is hard to sit still	0	1	2	3
6. Becoming easily annoyed or irritable	0	1	2	3
7. Feeling afraid as if something awful might happen	0	1	2	3

(For office coding: Total Score T____ = ____ + ____ + ____)

Developed by Drs. Robert L. Spitzer, Janet B.W. Williams, Kurt Kroenke and colleagues, with an educational grant from Pfizer Inc. No permission required to reproduce, translate, display or distribute.

Appendix I: Example consent forms



The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.
Doctor of Clinical Psychology (DClin Psy) Programme Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Sheffield S10 2TN UK

Consent Form 1

Title of Research Project: The Experience of Using a Facial Prosthesis

Name of Researcher: Iona Shepherd

Participant Identification Number for this project: Please initial box

1. I confirm that I have read and understand the information sheet dated .... explaining the above research project and I have had the opportunity to ask questions about the project. ☐
2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline. ☐
3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐
4. I agree for the anonymous data collected from me to be used in presentations, teaching, reports and journal articles ☐
5. I agree to take part in the survey part of this research project. ☐

(NB. If you agree to participate in the interviews, a separate consent form will be available at a later point)

__________________ ____________ _______________
Name of Participant Date Signature

__________________ ____________ _______________
Name of person taking consent Date Signature

The
University
Of
Sheffield.

Department Of Psychology.
Clinical Psychology Unit.
Doctor of Clinical Psychology (DClin Psy) Programme Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Sheffield S10 2TN UK

Consent Form 2

Title of Research Project: The Experience of Using a Facial Prosthesis

Name of Researcher: Iona Shepherd

Participant Identification Number for this project: **Please initial box**

1. I confirm that I have read and understand the information sheet dated .... explaining the above research project and I have had the opportunity to ask questions about the project. ☐

2. I understand that my participation is voluntary and that I am free to withdraw without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question, I am free to decline. ☐

3. I understand that my responses will be kept strictly confidential. I give permission for members of the research team to have access to my anonymised responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research. ☐

4. I agree for the anonymous data collected from me to be used in presentations, teaching, reports and journal articles. ☐

5. I agree for my photographs to be used anonymously for this research ☐

6. I agree to take part in the interview part of this research project. ☐

Name of Participant	Date	Signature
Name of person taking consent	Date	Signature

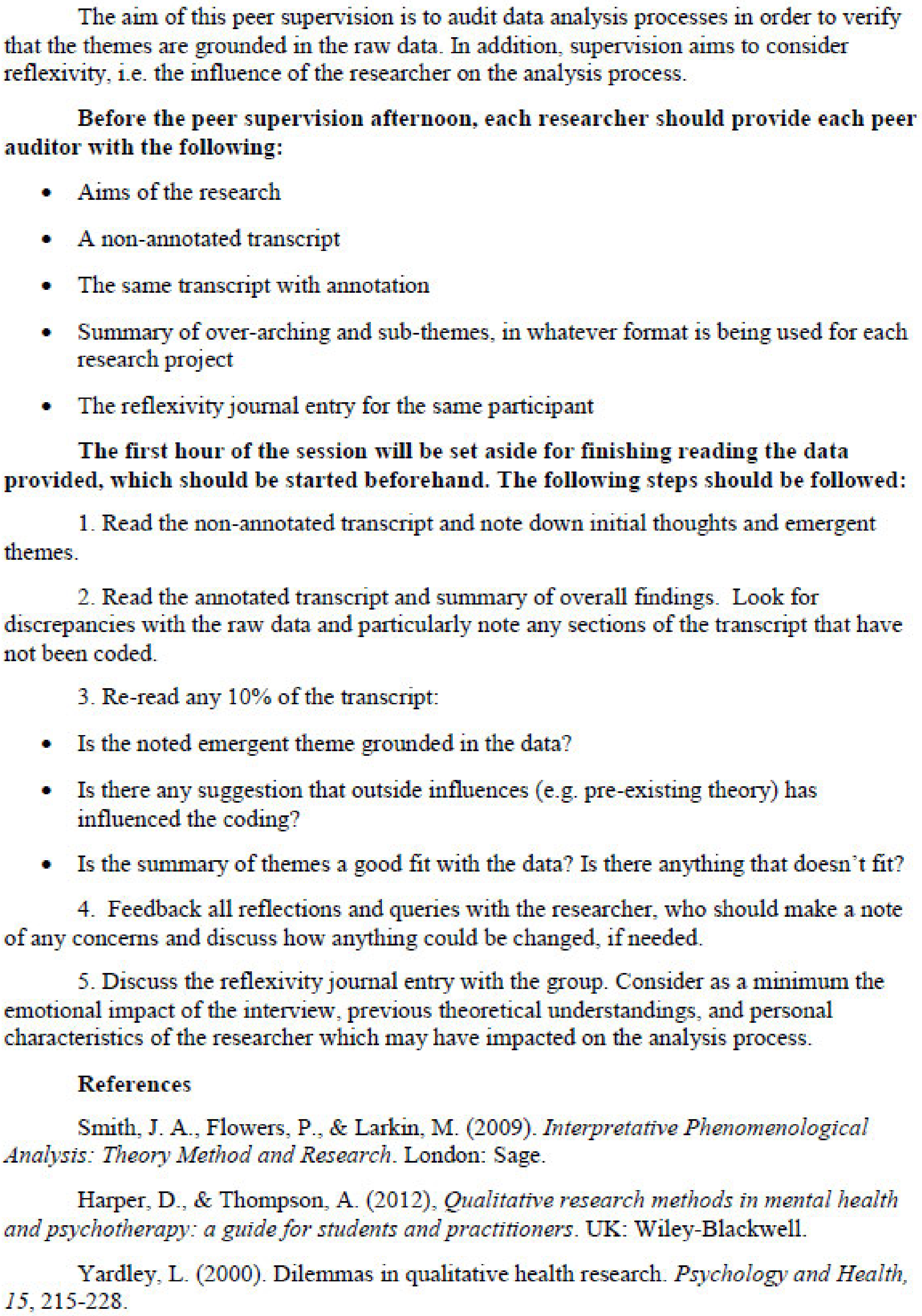
Appendix J: Example table of transcript, line-by-line coding, emergent and over-arching themes

Transcript	Line by line	Emergent theme	Superordinate theme
P: …And I was used to being in front of people and on stage and one thing and another, and I think that was all part of something that, you know, it doesn't faze me, if you like. If you said to me, "Would you come next door and stand in front of a group of students and they want to ask you questions?" I'd say, "Yeah, go on". Now that would be an interesting challenge to me. ***R:*** *Yeah, and that's down to your personality from before?* **P:** Yeah, yeah, because a lot of people would say, "Oh, no, I couldn't do that". ***R:*** *Yeah, and I'm wondering again what difference the prosthesis makes for you?* **P:** Well, it gives me a feeling of wellbeing, if you like. It makes me feel normal or as normal as possible, I suppose. But it makes me feel, well, outwardly like everybody else. What's inside is inside. What's inside is inside, but otherwise it doesn't bother me at all. ***R:*** *And what does it mean for you to be able to look outwardly like everybody else?* **P:** Well, I feel now that I'm back on the map and I'm doing what normal people do. It's like I don't wear collars and ties these days because I used to wear them all day, every day, but if you're going out somewhere and you're going out dressed up and you've got a nice collar and tie on, you feel good, and I feel… and that's how I feel when I've got my ear on.	Used to being centre of attention. Hasn't changed since HNC. Different from others – not everyone is confident. Prosthesis feels good; feel normal, like everyone else. Returning to previous self. Feel good factor, special feeling.	Confidence Premorbid personality helps Prosthesis brings normalcy Prosthesis enables Wellbeing with prosthesis	**Coping** – confident personality **Prosthesis** restores normalcy **Prosthesis** is enabling
P: And, well, look at my age. I'm lucky to still be here, still relatively minor thing if we put things in perspective. ***R:*** *Yeah, so there's a sense of perspective for you and it's not, in the scheme of things, you feel it's not a big deal?* **P:** No. But I could imagine that some people might feel very differently about it, women more than men. And certainly anywhere else on the face other than the ear, well, I suppose if I was a woman I'd just… or even if I was a man I could let my hair grow over it, but I've chosen not to do that. ***R:*** *Yeah, yeah, so you're happy for it to be visible and exposed?* **P:** Yeah, yeah, well, in fact, the majority of people are not aware of it until I point it out. "Good gracious," you know. ***R:*** *Yeah, tell me about that. What's the kind of… what reasons do you have and what situations for telling people about it?* **P:** Well, I think it arises mainly because I'm aware of so many friends and neighbours and so on that have cancer now and most of them, I mean they're much worse off than me.	Minimising? Appearance/prosthesis is minor cf cancer Luck/relief to be alive Imagines worse for women & not on ear Considers concealing, but chosen not to Prosthesis means it's not visible – people surprised (pleased?) Others worse off - cancer	Survival more important than appearance Gender difference Location of prosthesis Concealment – prosthesis as concealment? Lifelike & natural prosthesis Others worse off	**Cancer** – survival is priority **Coping** - Comparing to others **Prosthesis** restores normalcy
R: *Mmm, and what would it be like without it?* **P:** Well, I should have to wear an eyepatch and when, in a dry season, I have to make sure that it's covered and not get grit in it. It has to be cleaned. I have to clean it every day with	Maintenance, routines It's a burden? Cleaning	Ongoing practicalities	**Prosthesis –** practicalities are ongoing

a drop of cold water and splash it into the socket and just pat it down with the towel. **R:** *So, it needs a little bit of looking after?* **P:** Yeah, yeah. **R:** *Yeah. And the time when you have had to wear a patch, what was that like?* **P:** I felt like a latter-day pirate (laughter). **R:** *Okay (laughter). What do you mean?* **P:** It feels strange wearing an eyepatch. It makes you aware and people who knew you, who know you but didn't know your affliction, then they start asking questions. "What's happened? Have you injured your eye?" I have to go right back, start from square one, explain to them what happened and what's happening at present, up to getting a new prosthetic eye. **R:** *Yeah, and what does that feel like for you, having to explain all that?* **P:** Sometimes it can be embarrassing, or sometimes, well, I've had it for so long it's just like running a short lesson with somebody. So, I've done my best not to bother what people say about it. I just tell them what they want to know and not feel embarrassed about it.	Self as comic with dressing? Self-conscious with patch. Prosthesis stops attention? Others ask questions Have to explain Embarrassing Resignation? Explanation routine Trying not to bother	Humour/negative self-image? Self-consciousness Unwanted attention Explanations Embarrassing	**Coping** – Humour **Living with altered appearance** – negative self-image; unwanted attention
R: *So, what does that mean for you in that situation?* **P:** It doesn't bother me now, but there was an incident in the… when we were in the caravan of this couple came at the side of us, didn't they, an older couple, and he saw me in the awning with the dressing on. He just put his hand up and I put my hand up. And whilst we were sat in the afternoon having a coffee, he came to the awning, didn't he, and came in. I said, "Come in". I'd got my nose on then. And he said, "I'm not nosy," he said, "But I was concerned when I saw you this morning when you waved," and I said, "Oh, when I'd got my dressing on?" He said, "Yes". And they sat. I said, "Well, sit down". I said, "We'll make you a drink," I said, "Because you'll be here an hour or two". (laughter) So, of course we told him the story, and he kept saying, "Oh, I'm so sorry, dear," you know, he was a really nice person. But then his wife came to see where he was. So, she came in and had a drink of coffee and what have you. Well, she was listening to the conversation so she said, "I understand then from that that you've had your… you've been through the mill". So, I said, "Yes, I have a bit," I said, "But I'm glad to say I'm still here and able to enjoy life," which I was. But that was the first incident I'd had where… with being in the caravan. But now, you know, you just accept it. If you're outside with a dressing on, you're outside.	Adjustment – not bothered anymore Being seen with dressing not prosthesis Others are curious – ask questions Inviting others in – long explanations Sympathy – positive Perspective – still alive Learn to accept others' curiosity	Adjustment Others' curiosity, questions Supportive others Sympathy Survival is most important	**Living with altered appearance** – attention **Adjustment and coping** – supportive relationships **Cancer** – survival is priority
P: Yeah, I mean… People have said like, you know, "What have you done to your eye?" And then when I tell them like I've been blind since '88 and they didn't even know. But, it doesn't… like I say, it doesn't bother me. It doesn't bother me. But other people probably just wondering what I've done. **R:** *Yeah, and that… and did that kind of weigh on you a little bit what other people…?*	People ask questions People don't realise eye isn't real People are curious Emphasising not	Unwanted attention Questions – intrusion Explanations	**Living with altered appearance** – unwanted attention; negative self-image **Coping** - personality

P: No. ***R:*** *…because I guess I'm thinking you said it was going white so you wanted to change it…* **P:** It was… well, like I say, it wasn't bothering me, but I suppose deep down I was thinking about the other people that were looking. Rather than keep saying, you know, "What have you done?" and having to explain all the time. ***R:*** *Yeah, okay. So, was it a sense of… I might get this bit wrong… of not wanting to put other people out by making them ask lots, wanting to look more normal. Is that…?* **P:** Well, probably, yeah, yeah. I look at bit better, but it does, it evens your… you know, evens your face up, because if somebody's got like a blotch on their face or a mark, people are automatically drawn to it, whereas if you've got two eyes, you don't bother so much. ***R:*** *Yeah.* **P:** So, probably that's what triggered it off. But, like I say, I mean [spouse] says I'm too easy-going.	bothered – it's OK? …but is aware of other' thoughts. Questions Need to explain a lot Better self-image + prosthesis Face is even – not conspicuous Self as easy-going	Adjustment Self-conscious Self-image Personality	

Appendix K: Peer audit and reflexivity protocol



The aim of this peer supervision is to audit data analysis processes in order to verify that the themes are grounded in the raw data. In addition, supervision aims to consider reflexivity, i.e. the influence of the researcher on the analysis process.

Before the peer supervision afternoon, each researcher should provide each peer auditor with the following:

- Aims of the research
- A non-annotated transcript
- The same transcript with annotation
- Summary of over-arching and sub-themes, in whatever format is being used for each research project
- The reflexivity journal entry for the same participant

The first hour of the session will be set aside for finishing reading the data provided, which should be started beforehand. The following steps should be followed:

1. Read the non-annotated transcript and note down initial thoughts and emergent themes.

2. Read the annotated transcript and summary of overall findings. Look for discrepancies with the raw data and particularly note any sections of the transcript that have not been coded.

3. Re-read any 10% of the transcript:

- Is the noted emergent theme grounded in the data?
- Is there any suggestion that outside influences (e.g. pre-existing theory) has influenced the coding?
- Is the summary of themes a good fit with the data? Is there anything that doesn't fit?

4. Feedback all reflections and queries with the researcher, who should make a note of any concerns and discuss how anything could be changed, if needed.

5. Discuss the reflexivity journal entry with the group. Consider as a minimum the emotional impact of the interview, previous theoretical understandings, and personal characteristics of the researcher which may have impacted on the analysis process.

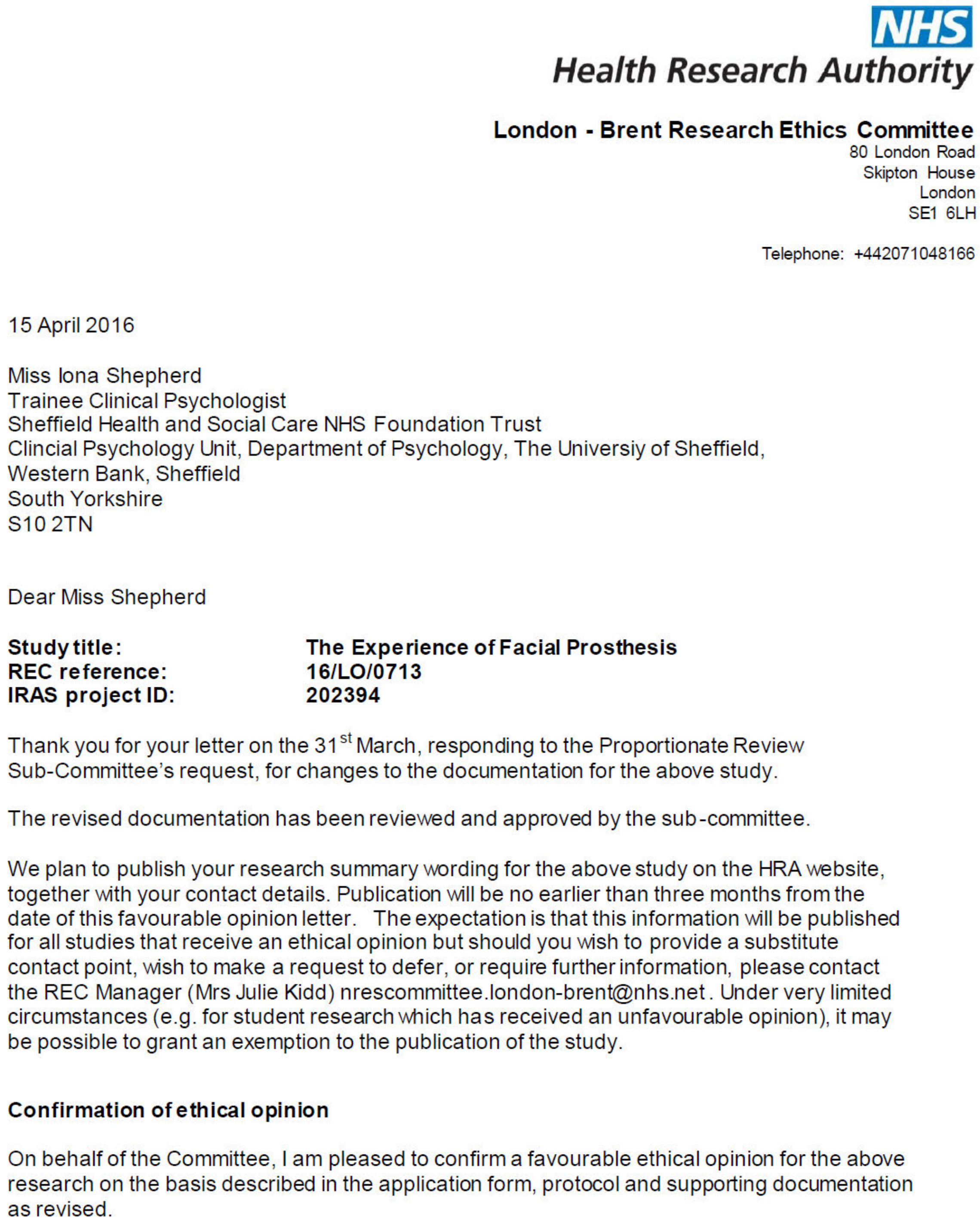
References

Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative Phenomenological Analysis: Theory Method and Research*. London: Sage.

Harper, D., & Thompson, A. (2012). *Qualitative research methods in mental health and psychotherapy: a guide for students and practitioners*. UK: Wiley-Blackwell.

Yardley, L. (2000). Dilemmas in qualitative health research. *Psychology and Health, 15*, 215-228.

Appendix L: REC ethical approval letter



NHS
Health Research Authority

London - Brent Research Ethics Committee
80 London Road
Skipton House
London
SE1 6LH

Telephone: +442071048166

15 April 2016

Miss Iona Shepherd
Trainee Clinical Psychologist
Sheffield Health and Social Care NHS Foundation Trust
Clincial Psychology Unit, Department of Psychology, The Universiy of Sheffield,
Western Bank, Sheffield
South Yorkshire
S10 2TN

Dear Miss Shepherd

Study title:	**The Experience of Facial Prosthesis**
REC reference:	**16/LO/0713**
IRAS project ID:	**202394**

Thank you for your letter on the 31st March, responding to the Proportionate Review Sub-Committee's request, for changes to the documentation for the above study.

The revised documentation has been reviewed and approved by the sub-committee.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact the REC Manager (Mrs Julie Kidd) nrescommittee.london-brent@nhs.net . Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation as revised.

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, www.hra.nhs.uk or at http://www.rdforum.nhs.uk.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

Registration of Clinical Trials

All clinical trials (defined as the first four categories on the IRAS filter page) must be registered on a publically accessible database. This should be before the first participant is recruited but no later than 6 weeks after recruitment of the first participant.

There is no requirement to separately notify the REC but you should do so at the earliest opportunity e.g. when submitting an amendment. We will audit the registration details as part of the annual progress reporting process.

To ensure transparency in research, we strongly recommend that all research is registered but for non-clinical trials this is not currently mandatory.

If a sponsor wishes to request a deferral for study registration within the required timeframe, they should contact hra.studyregistration@nhs.net. The expectation is that all clinical trials will be registered, however, in exceptional circumstances non registration may be permissible with prior agreement from the HRA. Guidance on where to register is provided on the HRA website.

Ethical review of research sites

The favourable opinion applies to all NHS sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

Document	*Version*	*Date*
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Sheffield Indemnity certificate]	1	04 March 2016
Interview schedules or topic guides for participants [Interview Schedules]	1	31 March 2016
IRAS Checklist XML [Checklist_30032016]		30 March 2016
IRAS Checklist XML [Checklist_31032016]		31 March 2016
IRAS Checklist XML [Checklist_14042016]		14 April 2016
Letter from sponsor [Letter of Scientific Approval]	1	18 February 2016
Letters of invitation to participant [Invitation Letter]	1	31 March 2016
Participant consent form [Consent forms]	1	31 March 2016
Participant consent form [Consent forms]	2	14 April 2016
Participant information sheet (PIS) [Information Sheet]	1	31 March 2016
Participant information sheet (PIS) [Participant Information Sheet]	2	14 April 2016
REC Application Form [REC_Form_30032016]		17 March 2016
Research protocol or project proposal [Research Protocol]	2	25 January 2016
Summary CV for Chief Investigator (CI) [CI CV]	1	15 March 2016
Summary CV for supervisor (student research) [Supervisor CV]	1	01 March 2016
Validated questionnaire [Survey (inc. validated questionnaires)]	2	31 March 2016

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

After ethical review

Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

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

Feedback

You are invited to give your view of the service that you have received from the National Research Ethics Service and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website:
http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance

We are pleased to welcome researchers and R & D staff at our NRES committee members' training days – see details at http://www.hra.nhs.uk/hra-training/

16/LO/0713	**Please quote this number on all correspondence**

With the Committee's best wishes for the success of this project.

Yours sincerely

PP

[redacted]

Chair

Manish Saxena

Email: nrescommittee.london-brent@nhs.net

Appendix M: HRA approval letter

NHS
Health Research Authority

Miss Iona Shepherd
Trainee Clinical Psychologist
Sheffield Health and Social Care NHS Foundation Trust
Clincial Psychology Unit, Department of Psychology, The
Universiy of Sheffield,
Western Bank, Sheffield
South Yorkshire
S10 2TN

Email: hra.approval@nhs.

17 August 2016

Dear Miss Shepherd,

Letter of <u>HRA Approval for a study processed through pre-HRA Approval systems</u>

Study title:	**The Experience of Facial Prosthesis**
IRAS project ID:	**202394**
Sponsor	**The University of Sheffield**

Thank you for your request for HRA Approval to be issued for the above referenced study.

I am pleased to confirm that the study has been given **<u>HRA Approval.</u>** This has been issued on the basis that the study is compliant with the UK wide standards for research in the NHS.

The extension of HRA Approval to this study on this basis allows the sponsor and participating NHS organisations in England to set-up the study in accordance with HRA Approval processes, with decisions on study set-up being taken on the basis of capacity and capability alone.

If you have submitted an amendment to the HRA between 23 March 2016 and the date of this letter, this letter incorporates the HRA Approval for that amendment, which may be implemented in accordance with the amendment categorisation email (e.g. not prior to REC Favourable Opinion, MHRA Clinical Trial Authorisation etc., as applicable). If the submitted amendment included the addition of a new NHS organisation in England, the addition of the new NHS organisation is also approved and should be set up in accordance with HRA Approval processes (e.g. the organisation should be invited to assess and arrange its capacity and capability to deliver the study and confirm once it is ready to do so).

Participation of NHS Organisations in England

Please note that full information to enable set up of participating NHS organisations in England is not provided in this letter, on the basis that activities to set up these NHS organisations is likely to be underway already.

The sponsor should provide a copy of this letter, together with the local document package and a list of the documents provided, to participating NHS organisations in England that are being set up in accordance with HRA Approval Processes. It is for the sponsor to ensure that any documents provided to participating organisations are the current, approved documents.

For non-commercial studies the local document package should include an appropriate Statement of Activities and HRA Schedule of Events. The sponsor should also provide the template agreement to be used in the study, where the sponsor is using an agreement in addition to the Statement of Activities. Participating NHS organisations in England should be aware that the Statement of Activities and HRA Schedule of Events for this study have not been assessed and validated by the HRA. Any changes that are appropriate to the content of the Statement of Activities and HRA Schedule of Events should be agreed in a pragmatic fashion as part of the process of assessing, arranging and confirming capacity and capability to deliver the study. If subsequent NHS organisations in England are added, an amendment should be submitted to the HRA..

For commercial studies the local document package should include a validated industry costing template and the template agreement to be used with participating NHS organisations in England.

It is critical that you involve both the research management function (e.g. R&D office and, if the study is on the NIHR portfolio, the LCRN) supporting each organisation and the local research team (where there is one) in setting up your study. Contact details and further information about working with the research management function for each organisation can be accessed from www.hra.nhs.uk/hra-approval.

After HRA Approval

In addition to the document, *"After Ethical Review – guidance for sponsors and investigators"*, issued with your REC Favourable Opinion, please note the following:

- HRA Approval applies for the duration of your REC favourable opinion, unless otherwise notified in writing by the HRA.
- Substantial amendments should be submitted directly to the Research Ethics Committee, as detailed in the *After Ethical Review* document. Non-substantial amendments should be submitted for review by the HRA using the form provided on the HRA website, and emailed to hra.amendments@nhs.net.
- The HRA will categorise amendments (substantial and non-substantial) and issue confirmation of continued HRA Approval. Further details can be found on the HRA website.

Scope

HRA Approval provides an approval for research involving patients or staff in NHS organisations in England.

If your study involves NHS organisations in other countries in the UK, please contact the relevant national coordinating functions for support and advice. Further information can be found at http://www.hra.nhs.uk/resources/applying-for-reviews/nhs-hsc-rd-review/.

If there are participating non-NHS organisations, local agreement should be obtained in accordance with the procedures of the local participating non-NHS organisation.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please email the HRA at hra.approval@nhs.net. Additionally, one of our staff would be happy to call and discuss your experience of HRA Approval.

HRA Training

We are pleased to welcome researchers and research management staff at our training days – see details at http://www.hra.nhs.uk/hra-training/.

If you have any queries about the issue of this letter please, in the first instance, see the further information provided in the question and answer document on the HRA website.

Your IRAS project ID is 202394. Please quote this on all correspondence.

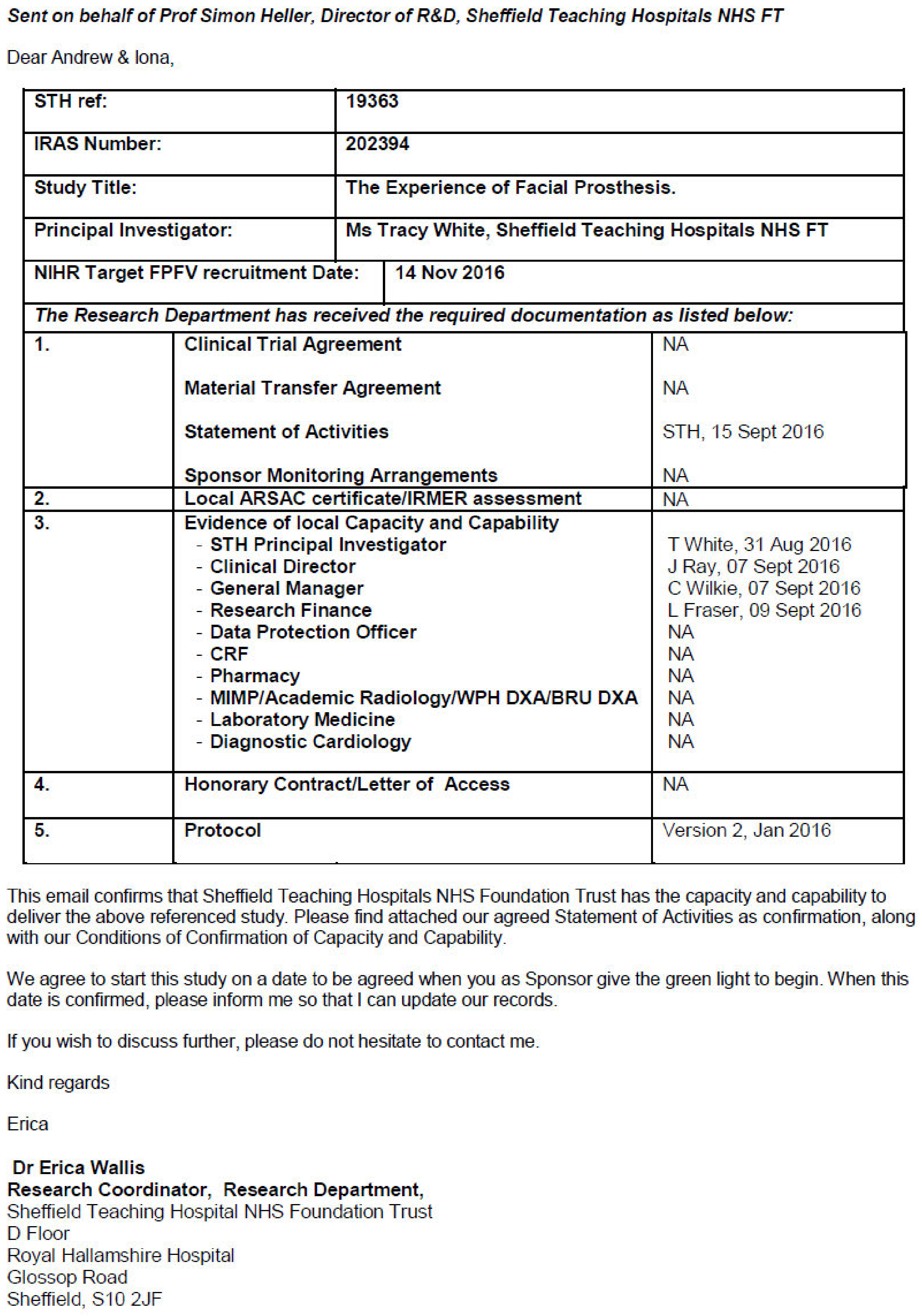
Yours sincerely

Simon Connolly
Senior Assessor

Email: hra.approval@nhs.net

Copy to: *Mr Amrit Sinha, University of Sheffield*
Dr Erica Wallis, Sheffield Teaching Hospitals NHS Foundation Trust

Appendix N: NHS trust governance approval e-mails



Sent on behalf of Prof Simon Heller, Director of R&D, Sheffield Teaching Hospitals NHS FT

Dear Andrew & Iona,

STH ref:	**19363**
IRAS Number:	**202394**
Study Title:	**The Experience of Facial Prosthesis.**
Principal Investigator:	**Ms Tracy White, Sheffield Teaching Hospitals NHS FT**
NIHR Target FPFV recruitment Date:	**14 Nov 2016**

The Research Department has received the required documentation as listed below:

1.	**Clinical Trial Agreement**	NA
	Material Transfer Agreement	NA
	Statement of Activities	STH, 15 Sept 2016
	Sponsor Monitoring Arrangements	NA
2.	**Local ARSAC certificate/IRMER assessment**	NA
3.	**Evidence of local Capacity and Capability**	
	- STH Principal Investigator	T White, 31 Aug 2016
	- Clinical Director	J Ray, 07 Sept 2016
	- General Manager	C Wilkie, 07 Sept 2016
	- Research Finance	L Fraser, 09 Sept 2016
	- Data Protection Officer	NA
	- CRF	NA
	- Pharmacy	NA
	- MIMP/Academic Radiology/WPH DXA/BRU DXA	NA
	- Laboratory Medicine	NA
	- Diagnostic Cardiology	NA
4.	**Honorary Contract/Letter of Access**	NA
5.	**Protocol**	Version 2, Jan 2016

This email confirms that Sheffield Teaching Hospitals NHS Foundation Trust has the capacity and capability to deliver the above referenced study. Please find attached our agreed Statement of Activities as confirmation, along with our Conditions of Confirmation of Capacity and Capability.

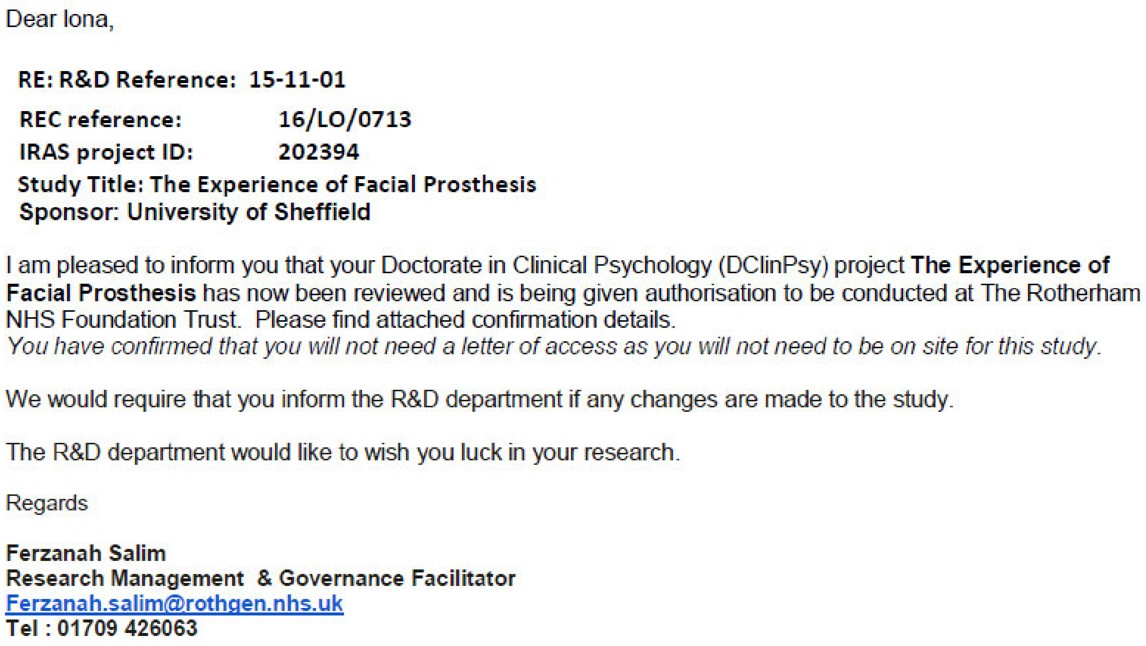
We agree to start this study on a date to be agreed when you as Sponsor give the green light to begin. When this date is confirmed, please inform me so that I can update our records.

If you wish to discuss further, please do not hesitate to contact me.

Kind regards

Erica

Dr Erica Wallis
Research Coordinator, Research Department,
Sheffield Teaching Hospital NHS Foundation Trust
D Floor
Royal Hallamshire Hospital
Glossop Road
Sheffield, S10 2JF



Dear Iona,

RE: R&D Reference: 15-11-01

REC reference: 16/LO/0713

IRAS project ID: 202394

Study Title: The Experience of Facial Prosthesis

Sponsor: University of Sheffield

I am pleased to inform you that your Doctorate in Clinical Psychology (DClinPsy) project **The Experience of Facial Prosthesis** has now been reviewed and is being given authorisation to be conducted at The Rotherham NHS Foundation Trust. Please find attached confirmation details.
You have confirmed that you will not need a letter of access as you will not need to be on site for this study.

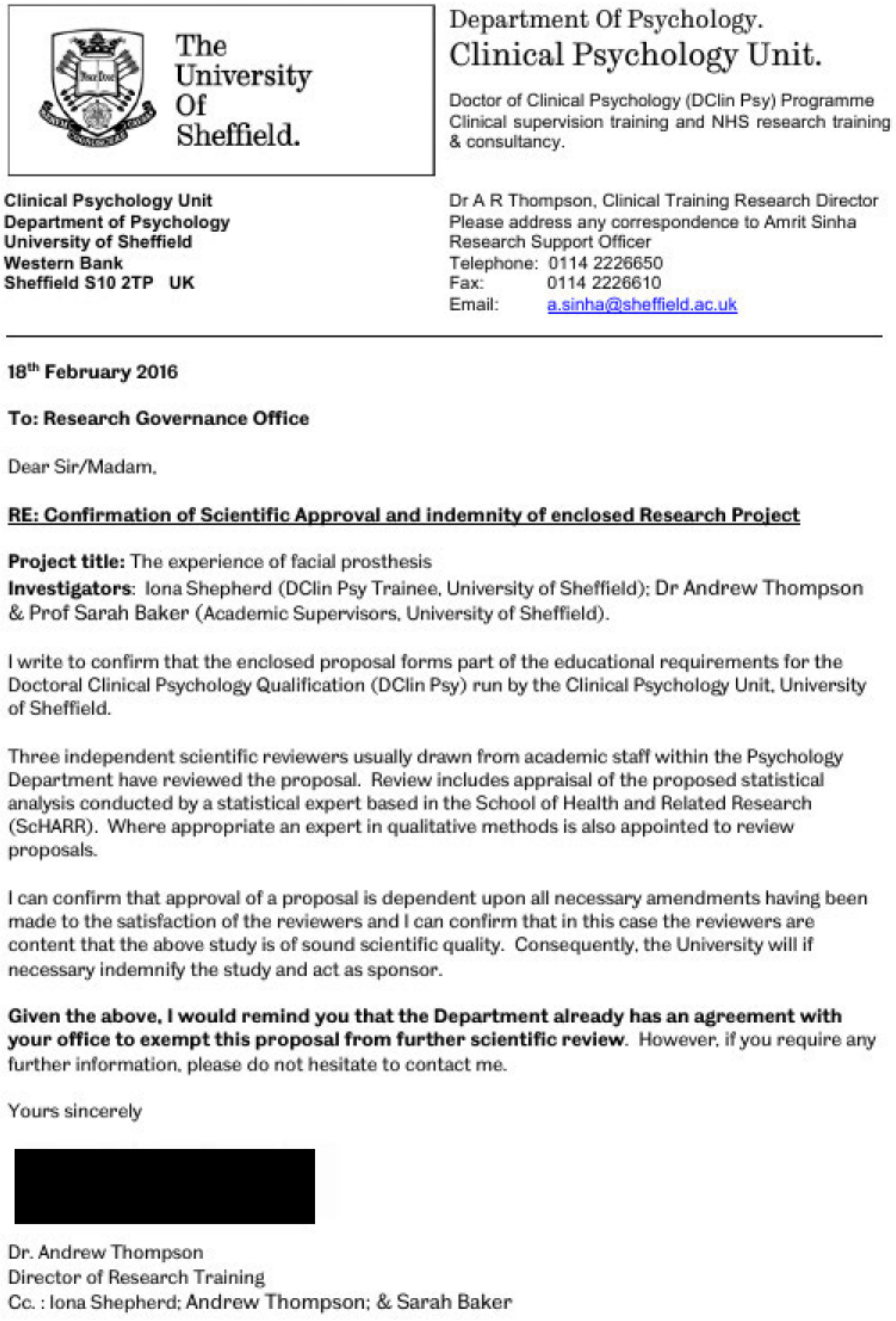
We would require that you inform the R&D department if any changes are made to the study.

The R&D department would like to wish you luck in your research.

Regards

Ferzanah Salim
Research Management & Governance Facilitator
Ferzanah.salim@rothgen.nhs.uk
Tel : 01709 426063

Appendix O: University ethics and scientific approval letter



The University Of Sheffield.

Department Of Psychology.
Clinical Psychology Unit.

Doctor of Clinical Psychology (DClin Psy) Programme
Clinical supervision training and NHS research training & consultancy.

Clinical Psychology Unit
Department of Psychology
University of Sheffield
Western Bank
Sheffield S10 2TP UK

Dr A R Thompson, Clinical Training Research Director
Please address any correspondence to Amrit Sinha
Research Support Officer
Telephone: 0114 2226650
Fax: 0114 2226610
Email: a.sinha@sheffield.ac.uk

18th February 2016

To: Research Governance Office

Dear Sir/Madam,

RE: Confirmation of Scientific Approval and indemnity of enclosed Research Project

Project title: The experience of facial prosthesis
Investigators: Iona Shepherd (DClin Psy Trainee, University of Sheffield); Dr Andrew Thompson & Prof Sarah Baker (Academic Supervisors, University of Sheffield).

I write to confirm that the enclosed proposal forms part of the educational requirements for the Doctoral Clinical Psychology Qualification (DClin Psy) run by the Clinical Psychology Unit, University of Sheffield.

Three independent scientific reviewers usually drawn from academic staff within the Psychology Department have reviewed the proposal. Review includes appraisal of the proposed statistical analysis conducted by a statistical expert based in the School of Health and Related Research (ScHARR). Where appropriate an expert in qualitative methods is also appointed to review proposals.

I can confirm that approval of a proposal is dependent upon all necessary amendments having been made to the satisfaction of the reviewers and I can confirm that in this case the reviewers are content that the above study is of sound scientific quality. Consequently, the University will if necessary indemnify the study and act as sponsor.

Given the above, I would remind you that the Department already has an agreement with your office to exempt this proposal from further scientific review. However, if you require any further information, please do not hesitate to contact me.

Yours sincerely

[redacted]

Dr. Andrew Thompson
Director of Research Training
Cc. : Iona Shepherd; Andrew Thompson; & Sarah Baker