

Visible Difference and Intimacy Workshop

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<u>Visible Difference and Intimacy Workshop</u> Summary of information in presentations

Polite Notice

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Background to the workshop

Romantic relationships and intimacy are important aspects of many people's lives. Whilst research has explored the psychological and social consequences of living with an altered appearance or an appearance altering condition (visible difference) and the idea that how we look may influence our perceptions of and judgements about one another, we know relatively little about how visible difference may impact upon feelings and experiences of romantic relationships and physical intimacy.

Workshop aim

• To explore the impact of visible difference upon intimate and romantic life

Workshop objectives

- To (re)introduce the impact of visible difference upon people's lives
- To examine research conducted in the sphere of romantic relationships and intimacy
- To reflect upon what support may be available to those with a visible difference
- To suggest how the topic can be broached in a sensitive manner before
- To consider what the key elements of an effective intervention aimed at alleviating concerns related to visible difference and romantic relationships should be

Visible difference: the impact (Professor Nichola Rumsey)

Appearance in context

- Our interest in looks has a long history
- Appearance 'norms' have changed over time
- The emphasis placed on looks has never been stronger
 - Appearance ideals are becoming more extreme and unachievable
 - o Individuals must strive to achieve these ideals
 - This is effortful and requires 'work' such as cosmetic practices and surgery, dieting, exercise
 - o Diversity in appearance has become less acceptable
- Appearance messages are perpetuated by our social, media, and social media environments
- Achieving appearance ideals is often believed to be associated with many positive effects
 - Happiness
 - Relationship success
 - Social success
 - Occupational success

Visible difference

- Associated with higher distress than in general population
- Those with visible difference may experience other appearance concerns (weight, shape)

Adolescence and visible difference

- Appearance dissatisfaction influenced by
 - Peers (teasing / bullying)
 - Online environment (social media / video games)
 - Family
 - Teachers
 - Healthcare providers
- Challenges experienced by significant minority can include
 - Social functioning (teasing / bullying / unwelcome attention & questions / concerns about social relationships / changing social groups)

- Self-perceptions (body image / self-esteem / confidence)
- Health (physical health / psychological wellbeing / educational performance)

Adulthood and visible difference

- Appearance dissatisfaction influenced by
 - Media (broadcast / print / advertising / social media)
 - Peers (perceived norms)
- Challenges experienced by significant minority can include
 - Social functioning (staring / unwanted questions / stereotyping / avoidance / relationships)
 - Psychological well-being (self-consciousness / social anxiety / self-esteem / confidence / social avoidance & isolation)
 - Employment
 - Physical health (appearance dissatisfaction and health risk factors)

Adjustment to visible difference

- People of any appearance, age, gender or social background can be anywhere on a continuum between being very satisfied and very dissatisfied with the way they look
- The nature or severity of a visible difference is not a good predictor of adjustment
- Liable to dissatisfaction and adjustment difficulties where self-esteem is predominantly derived from appearance

Theoretical approaches

- Evolutionary
 - Natural selection drives preferences and choices
 - Innate preference for symmetrical and 'healthy' face and body
 - Attractiveness = occupational and social benefits
- Psychological
 - Stigma: marked as 'spoiled' and of less value, results in shame / low selfesteem / social avoidance / concealment
 - Objectification: treated as an object, internalisation, negative self-concept, vigilance, rumination, distress, interpretative bias
 - Fear avoidance (Newell: 1999, 2000): anxiety and fear, exposure v avoidance, habituation and skills v generalisation of anxiety and avoidance, integration v isolation

- Social-psychological
 - Biases: social information, attentional and interpretative, social anxiety, fear of negative evaluation
- Appearance Research Collaboration Model (in Rumsey & Harcourt, 2012; Clarke et al., 2014)
 - Predisposing factors (inc. peer influence, societal / media influence, gender, relationship status)
 - Intervening cognitive processing (inc. dispositional style, socio-cognitive processing, appearance specific cognitions)
 - o Outcomes (inc. social anxiety, social avoidance, shame, intimacy)

Activity

- Delegates were asked to complete a writing task examining the impact of visible difference on a hypothetical individual and feedback t the group
- This was referred to on an ongoing basis during the session

Visible difference and romantic life (Nicholas Sharratt)

Background

- · Under researched area
- Disorganised literature
 - o Referred to / small component of numerous articles
 - Often included in condition specific literature rather than visible difference literature
- Focus on three main CAR studies

Romantic relationships

- May include varying levels of love, intimacy, and dyadic closeness
- Typified by (Collins et al., 2009)
 - Distinctive intensity
 - Expressions of affection
 - Current / anticipated sexual behaviour
- · Close, satisfying, and desired sexual and social relationships associated improved
 - Health
 - o Happiness
 - Functioning
 - Sense of meaning
- Love and belonging, intimacy, affection, and love are major components of the third level (and first psychological level) of Maslow's hierarchy of needs

Visible difference and romantic relationships

- Potentially impact judgements made by *the other* as to attractiveness
- Potentially influence feelings about the self
- Existing research suggests
 - Significant minority report relational / sexual difficulties
 - Participants can feel unattractive /on outside beauty norm, fear negative evaluation & rejection, rely on concealment and avoidance

CAR Study #1 (Griffiths et al., 2012)

Visible difference and romantic relationships: Adolescents

Method

- Mixed methods, on-line, written study
- 40 participants (22 boys/men) aged 13-20
- Variety of conditions including
 - o Cleft x 27
 - Dermatological conditions x 9
- Analysed by inductive thematic analysis (Braun & Clarke, 2006)

Quantitative findings

- 29/40 experience of boyfriend / girlfriend
 - o 7/29 feel prevented intimacy with partner
- 9/40 currently in relationship
- 28/31 single participants wanted relationship
- 17/40 concerns re current / future relationships
- 23/40 confident re future relationships

Qualitative Findings: Romantic concerns

- Appearances are important
 - Attractiveness central in securing relationship, especially for teenagers
- I am unattractive (to others)
 - Some hopelessness though some believe this will be less important when older
- Fear of negative evaluation
 - o Anticipate negative responses
 - Reduce confidence in initiation
 - Challenging despite no actual experiences of negative reactions from romantic partners
- Concealment and avoidance
 - Via clothes, make-up, avoiding exposure
 - helpful in short term (only)
- Teasing and Bullying
 - Reinforced perception as unattractive
 - Reduced self-esteem and confidence
- Difficulty talking to the other sex
 - Reduced opportunities
 - Feelings persisted despite previous success

Qualitative Findings: Protective factors

- Good social skills
 - Connected to high self-efficacy in romantic relationships
- 'People don't notice it'
 - Belief helped to not feel self-conscious and to not consider attractiveness impacted
- 'Feeling unattractive is normal for teens'
 - Normalise such feelings regardless of appearance
- Valuing other attributes
 - o Importance of other attributes such as having a 'good personality'
- It's part of who I am
 - o Unique, celebrate difference, not deterrent to relationship
 - o Tendency towards making downward social comparisons 'it could be worse...'
- 'I'm in control'
 - o Being dismissive of those prioritising appearance
- Perceptions of social support
 - Friends, family, partners
 - Other sex friends reinforce acceptance

Conclusions

- Romantic concern typified by
 - Belief that attractiveness is valued in romantic relationships
 - High investment in appearance and belief that others evaluate on this basis
 - Concealment and avoidance
 - o Inhibited communication
- Romantic self-efficacy typified by
 - Valuing non-appearance attributes in attracting partner
 - Valuing other aspects of self
 - Normalising romantic anxieties
 - Deploying good social skills
- Tentative support for relevance of Appearance Research Collaboration Model (in Rumsey & Harcourt, 2012; Clarke et al., 2014)

CAR Study #2 (Sharratt et al., under review)

Visible difference and romantic relationships: Adults

Method

- Semi-structured interviews, phone / face-to-face / skype
- 22 participants (16 women), aged 25-64
- 10 conditions including
 - o Cleft x 6
 - Alopecia x 5
 - Dermatological conditions x 4
 - Breast cancer scarring x 2
- Analysed by inductive thematic analysis (Braun & Clarke, 2006)

Findings (themes)

- Appearance Attracts and Detracts
 - Looking to Love
 - Judgements made by others re: attractiveness and desirability
 - Represent barrier to relationship formation
 - Reflect gendered, prevalent social ideals
 - The Discounted Self
 - Internalised value judgements, assess self as devalued
 - Offer other valued attributes to partner (wealth / youth / personality)
 - Accepted 'despite' difference (by someone special, grateful, lucky)
- Looking Different: Physicality and Physical Reality
 - The Disclosure Dilemma
 - When not normally visible
 - Uncertainty: if / when / how to disclose to new partner
 - Negative reactions feared and experienced
 - Invading Physical Intimacy
 - Reduced desire and activity as feel unattractive
 - Cover up and conceal, even from loving partner
 - Sexual self-consciousness, during physical intimacy
 - Our Selfish Genes
 - Potentially heritable conditions
 - Impact on child's life, especially daughter
 - Contemplate continuation of pregnancy

- Looks Help Delineate and Define Intimate Relationships
 - The Litmus Test
 - Response of potential partner as speaking to their character
 - Desire / require empathy and compassion
 - Indicator of relationship potential
 - Enriching and fortifying us
 - Partner acceptance, trust, confidence
 - Establishes relationship as enduring and 'deep'
 - Positive impact of difference on individual filter into relationships
 - Treasured Support
 - Value partner support, protective
 - Partner not see / not care about difference
 - But possible communication barrier, may be hard to discuss impact

Conclusions

- Visible difference understood impact adults as well as adolescents
- Can spans:
 - o attraction / initiation
 - o early interactions
 - physical intimacy
 - life of relationship
- Challenges experienced but also potential for positive
- Indicate more support required
- Tentative support for theories / concepts of
 - o Stigma
 - o Objectification
 - Attentional bias (fear of negative evaluation / social anxiety)
 - Fear avoidance
 - Social skills
 - Appearance Research Collaboration Model (in Rumsey & Harcourt, 2012; Clarke et al., 2014)

CAR Study #3 (Sharratt et al., unpublished data)

Visible difference and romantic relationships: Adults

Method

- Develop (brief) visible difference, appearance distress, and romantic relationships scale
- CAR Romantic Relationships and Intimacy Scale (CARRIS)
- On-line questionnaires
- 74 grouped Likert style items
- >250 useable responses
- Exploratory factor analysis to identify latent constructs and reduce item numbers
- Iterative process
- Resulting structure of scale confirmed by confirmatory factor analysis with approx. 150 new responses

Findings

- 17 item, 3 factor scale
- 1st factor: sexual anxiety / self-consciousness
 - o e.g. 'I feel comfortable with my appearance in sexual situations'
- 2nd factor: romantic negative evaluation
 - o e.g. 'A new partner would be put off me by my appearance'
- 3rd factor: benefitting from partner support / understanding
 - o e.g. 'Speaking about how I look with a partner would be a positive experience'
- Correlations with all other measures employed, of
 - o Female/male self-consciousness during physical intimacy
 - Appearance distress / anxiety
 - Fear of intimacy
 - Fear of negative evaluation
 - Social intimacy (negative correlation)
- CARRIS total minimum possible = 0, maximum = 102, mean =59
- Significant differences?
 - Visibility of difference, no significant difference
 - Age / yrs since acquired, no significant difference
 - Sex: women scored 'worse' (more challenging) than men
 - o Treatment: those currently receiving treatment scored 'worse' that those not

- Cause of difference: (injury, congenital etc) no significant difference
- o Nature of difference: few significant differences but
 - Alopecia and multiple causes both 'worse' than other
- o Location of difference: few significant differences but
 - Limbs & head / face (multiple locations) 'worse' than limbs alone
- Relationship status: single 'worse' than in a relationship and living together
 - Married = between the two, not significantly different to either

Conclusions

- Adds to qualitative work
- Demonstrates structure of CARRIS and utility as research tool
- Suggests some group differences e.g. women/men but that visibility, cause, nature, location of difference is not associated with romantic challenges
 - o Note: no objective measure of severity was possible in this study
- · Signals romantic relationships as potentially difficult area
- Intimates that intervention may be helpful

Supporting our members

- Some adult participants (in qualitative work) also felt
 - No visible difference = difficult to fully empathise
 - Those close to become familiar / accustomed to difference
 - Others may underestimate day-to-day impact
- Sometimes a lack of support re visible difference and visible difference and intimacy from
 - o family
 - o friends
 - o healthcare professionals
- Would like more professional support available but peer-to-peer / expert patient preferred
- Delegates were encouraged to reflect on these questions
 - Where should / could someone with romantic / intimate concerns turn?
 - O What support / information is available?
 - o Is romance / intimacy ever mentioned by members / patients?
 - o What relevant experiences have you had (anonymously)?
 - What do/would you do if someone approached you for support?

Introducing the Ex-PLISSIT model (Bruna Costa)

Background

- Talking about sex and intimacy can be challenging but it is important that people are given the opportunity to discuss these issues
- These issues may not be discussed in routine practice
- The Ex-PLISSIT model (Davis & Taylor, 2006; Taylor & Davis, 2007), a revision of PLISSIT (Annon, 1976), is useful for discussing appearance-related concerns (Clarke et al, 2014)
- The model is a stepped-care model, patient need and healthcare professional expertise increase at each stage
- The model offers guidance for everyday clinical consultation and can be of value in helping to facilitate discussions around the subject of sex
- It may have utility outside of the clinical consultation, especially its earlier stages

The Ex-PLISSIT Model

- Comprises
 - I. **P**ermission Giving

Providing the patient with the opportunity to discuss sex and intimacy, but not compelling them to do so. Permission is explicit and ongoing in all subsequent communications

II. Limited Information

The provision of information that is relevant to the situation and concerns of the patient. This may include details of other sources of support and resources

III. Specific Suggestions

Identify specific challenges the patient may have, offering tailored support. Onward referral and specialist support become more appropriate

IV. Intensive Therapy

The provision of specialist therapy and care by specialist practitioners

- Ex-PLISSIT places explicit permission giving at the core of the interaction, all stages are dependent upon the provision of permission
- Permission giving techniques includes (McInnes, 2003)
 - Routine questioning
 - Generalising
 - Using statistics
 - Normalising
 - Open ended questions

- Limited information may include information focussing on how a condition or appearance concerns may impact upon sexuality and romantic life as well as sexual function
- Delegates were encouraged to conduct a simulated conversation using the Ex-PLISSIT model

Evaluation

- Critical evaluation of the model suggests that
 - It offers a structured model of interaction, codifying good clinical practice and interactions
 - It may help introduce the topic and 'break the ice'
 - The first two stages may be capable of general use
 - A lack of onward referral routes, resources and specialist practitioner may undermine the later stages

Effective Interventions (Nicholas Sharratt)

- CAR Framework of Appearance Related Interventions
 - Lower levels = less intense but able to impact more people
 - Ex-PLISSIT sits at level 1 (e.g. targeted campaigns, health professional training)
 - \circ Level 2 (e.g. stand-alone interventions and self-help manuals) includes FACE IT

FACE IT (Bessell et al.: 2012; 2010)

Structure

- Unsupervised, on-line, computerised cognitive behavioural training and social interaction skills training for those with a visible difference
- 8 x 1hr sessions, inc.
 - Non-verbal communication
 - Verbal communication
 - Goal setting
 - Negative automatic thoughts
 - Social skills
 - o Exposure

Intimacy

- Intimacy included within session 5: (SMART) Goal Setting
 - Specific
 - Measurable
 - Achievable
 - Realistic
 - Time-frame appropriate
- Sessions includes material aimed at
 - Normalising concern
 - o Catch, check, change negative thoughts
 - Respond to scenarios
 - SMART goal planning example getting intimate
 - o Providing positive models of others' experiences

Evaluation

Intimacy not separately measured / assessed

- Compared v. Non-intervention control v. face to face (f-2-f) cognitive behavioural training (by experienced, supervised therapist (not clinical psychologist))
- Evaluated @ 6 month follow up both Face IT & f-2-f (v control) = reduced
 - o anxiety & depression
 - o appearance concern
 - fear of negative evaluation
 - body image quality of life (f-2-f only)
- No significant differences f-2-f v Face IT
- Slight trend toward f-2-f (and especially at immediate assessment and 3 month follow up)
- Suggest effective despite being compared to a level 4 (counselling / therapy from a specialist) f-2-f intervention

YP FACE IT (Williamson, Griffiths & Harcourt, 2015; Williamson et al., 2016; Hamlet, Williamson & Harcourt, 2017)

- Adapted FACE IT for use by 12-17 year olds
- Envisages supervision by healthcare professionals (e.g. GP staff)
 - Minimal training required
 - Level 3 of CAR Framework of Appearance Related Interventions (selfadministered intervention facilitated by a trained professional)
- Romantic relationships in SMART Goals session
- Training for healthcare professionals may be required (raise / identify when may be beneficial)
- Efficacy being assessed

Activity

- Delegates were asked to consider what an effective intervention specifically targeting visible difference and romantic relationships / physical intimacy would look like?
 - o form / format
 - method of delivery / access
 - o level in CAR framework
 - healthcare professional involvement
 - peer involvement
 - o content
 - approach
 - o cost
 - o access

Summary and close

- The workshop aim and objectives were reviewed
- With thanks to the Vocational Training Charitable Trust Foundation (VTCTF) and the Appearance Collective for funding and convening this workshop and for supporting the research and the work of CAR.

Podcast

- Two members of CAR produce a monthly podcast which features episodes dedicated to many topics associated with visible difference, appearance, and body image. Find it here
- Episode 24 focusses on visible difference and romantic relationships. Get it here

References

- Annon, J. S. (1976). The PLISSIT model: A proposed conceptual scheme for the behavioral treatment of sexual problems. *Journal of sex education and therapy*, 2(1), 1-15.
- Bessell, A., Brough, V., Clarke, A., Harcourt, D., Moss, T. P., & Rumsey, N. (2012). Evaluation of the
 effectiveness of Face IT, a computer-based psychosocial intervention for disfigurement-related
 distress. *Psychology, health & medicine*, 17(5), 565-577.
- Bessell, A., Clarke, A., Harcourt, D., Moss, T. P., & Rumsey, N. (2010). Incorporating user perspectives in the design of an online intervention tool for people with visible differences: Face IT. Behavioural and Cognitive psychotherapy, 38(5), 577-596.
- Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative research in psychology*, 3(2), 77-101.
- Clarke, A., Thompson, A. R., Jenkinson, E., Rumsey, N., & Newell, R. (2014). *CBT for appearance anxiety: psychosocial interventions for anxiety due to visible difference*. John Wiley & Sons.
- Collins, W. A., Welsh, D. P., & Furman, W. (2009). Adolescent romantic relationships. *Annual Review of Psychology*, 60, 631-652.
- Davis, S., & Taylor, B. (2006). From PLISSIT to ex-PLISSIT. In *Rehabilitation: the use of theories ad models in practice* Davis S (Ed) Elsevier Health Sciences, pp. 101-129.
- Griffiths, C., Williamson, H., & Rumsey, N. (2012). The romantic experiences of adolescents with a visible difference: Exploring concerns, protective factors and support needs. *Journal of Health Psychology*, 17(7).
- Hamlet, C., Williamson, H., & Harcourt, D. (2017). Recruiting young people with a visible difference to the YP face IT feasibility trial: A qualitative exploration of primary care staff experiences. *Primary Health Care Research & Development*, 18(6), 541-548.
- McInnes, R. A. (2003). Chronic illness and sexuality. *Medical Journal of Australia*, 179(5), 263-266.
- Newell, R. (2000). Body image and disfigurement care Psychology Press.
- Newell, R. J. (1999). Altered body image: A fear-avoidance model of psycho-social difficulties following disfigurement. *Journal of Advanced Nursing*, 30(5).
- Popovic, M. (2005). Intimacy and its relevance in human functioning. *Sexual and Relationship Therapy*, 20(1), 31-49.
- Rumsey, N., & Harcourt, D. (2012). *Oxford handbook of the psychology of appearance* Oxford University Press.
- Sharratt, N.D., Moss, T.P., Jenkinson, E., Clarke, A., and Rumsey, N. (2018) Development and Initial Validation of the CAR Romantic Relationships and Intimacy Scale (unpublished data)
- Sharratt, N.D., Jenkinson, E., Moss, T.P., Clarke, A., and Rumsey, N. (2018) Understandings and experiences of visible difference and romantic relationships: A qualitative exploration *(under review)*
- Taylor, B., & Davis, S. (2007). The extended PLISSIT model for addressing the sexual wellbeing of individuals with an acquired disability or chronic illness. *Sexuality and Disability*, 25(3), 135-139.

- Williamson, H., Griffiths, C., & Harcourt, D. (2015). Developing young person's face IT: Online psychosocial support for adolescents struggling with conditions or injuries affecting their appearance. *Health Psychology Open*, 2(2).
- Williamson, H., Hamlet, C., White, P., Marques, E. M., Cadogan, J., Perera, R., . . . Harcourt, D. (2016). Study protocol of the YP face IT feasibility study: Comparing an online psychosocial intervention versus treatment as usual for adolescents distressed by appearance-altering conditions/injuries. *BMJ Open*, 6(10).