

Appearance Research News

The Newsletter of the Centre for Appearance Research – Issue 9

Welcome...

...to the Centre for Appearance Research (CAR).

In this issue we celebrate funding success, a number of PhD completions and the success of Appearance Matters 3. Including a special feature on 'the psychosocial impact of breast cancer diagnosis and treatment amongst black and minority ethnic (BME) women' by Geeta Patel.

Headlines



Funding

We are delighted to report that The Vocational Training Charitable Trust (VTCT) has awarded CAR £550,000 over 5 years to fund two research fellows. One Fellow will be appointed to work in the area of interventions for people with appearance concerns, the second will be in the area of public education/attitude change. As a condition of the award, Nicky Rumsey's title will change to the VTCT Professor of Appearance Psychology.

Appearance Matters™ 3

The 2-day conference held in Bristol in July 2008 was a great success. It attracted 192 delegates including many from Australia, New Zealand, America, Canada, Norway, Sweden and Malaysia, in addition to those from across Europe and the UK. The conference included keynote addresses by Professor Marika Tiggemann, Flinders University, Australia and our very own Professor Nichola Rumsey, UWE, both of whom are internationally renowned for their work on body image and visible difference. Many thanks to members of CAR who worked so hard to make the conference such a success and to The Healing Foundation for their generous support.

Size Matters?

CAR is hosting a one day meeting on Monday 22 June 2009 to explore psychosocial issues around weight and obesity from a variety of perspectives. It covers current medical, psychosocial and critical approaches to understanding and managing body weight. For further details see <http://science.uwe.ac.uk/sizematters/>

Inside this issue

Headlines	1	CAR Events	2
Congratulations	2	Research Overview	3
New Members	2	Recent Publications	5
CAR in the Media	2	Knowledge Exchange and	
CAR News	2	Public Education	6

Congratulations...

We have had a flurry of very successful PhD vivas over the past year. Many congratulations to Dr Fiona Fox (supervised by Marianne Morris & Nicky Rumsey), Dr Ben Rosser (supervised by Tim Moss & Nicky Rumsey), Dr Sue Jackson (supervised by Marianne Morris & Nicky Rumsey) and Dr Jamie White (supervised by Emma Halliwell, Tim Moss & Nicky Rumsey).



New Members...



We are delighted to welcome:

Geeta Patel, who joined us at the start of October 2008 to carry out a PhD funded by Breast Cancer Campaign to research Black Minority Ethnic (BME) women's experiences following breast cancer diagnosis, with a focus on appearance issues. Geeta will be supervised by Di Harcourt, Nicky Rumsey and Habib Naqvi (Bristol PCT).

Chantelle Bailey is helping Tim Moss, Heidi Williamson and Rebecca Bellew to develop a measure of appearance related distress of children and young people.

CAR in the Media

Several members of CAR contributed to the ITV programme "The Great British Body" hosted by Trinny and Susannah which was aired during July 2008.

Nichola Rumsey contributed to BBC's documentary 'Jess: My New Face' which has been shown several times in the last few months on BBC One and BBC Three.

Funding Success

Congratulations to Diana Harcourt, who was awarded £9900, from North Bristol NHS Trust, for a 6 month feasibility study of a breast reconstruction decision aid. This study will develop some of Di's work with Kerry Sherman in Sydney. Heidi Williamson began working on this study in December 2008.

Changing Faces have been awarded £300,000 over 2 years to develop and evaluate new curriculum resources for year 8/9 students to promote inclusive social skills (including attitudes and behaviours towards people with an altered facial appearance). Their funding proposal includes a 0.4FTE researcher to be supervised by CAR.

CAR News

SciFest'08, St Louis, Missouri

Nicky Rumsey was invited to present the following three talks at a science festival held in St Louis, Missouri:

- Is beauty in the eye of the beholder?
- Busting beauty myths: the impact of appearance in everyday life
- Busting beauty myths: a users guide

CAR Events

Autumn 2008 Away Day

Elizabeth Jenkinson, Heidi Williamson and Emma Williams presented a session on 'Designing and evaluating interventions'.

Spring 2009 Away Day

Heidi Williamson has arranged a two day science communication workshop for all CAR members. The workshop will be run by the Science Communication Unit, UWE, and the sessions have been tailored to the needs of CAR.

Invited CLIC Sargent Workshop

Heidi Williamson, Diana Harcourt and Emma Halliwell were invited to run a workshop 'Appearance concerns for adolescents with cancer - Can research inform practice?'. Health professionals and researchers from the South West, who work with young people with cancer, were invited to attend the workshop. During this session attendees heard the findings of a recently completed project funded by CLIC Sargent: 'Exploring the experiences of adolescents, and their parents, experiences of an altered appearance during treatment for cancer'. Attendees were asked to discuss their experiences of this issue and to contemplate how the research findings might inform practice and the care of adolescent cancer patients with appearance concerns.

Attendees acknowledged that appearance is an important and legitimate issue for patients and parents, and that appearance concerns can have potentially far-reaching consequences. They were unanimous in voicing their opinion that some patients need further support to help them manage these concerns. Potential interventions and suggestions of how professionals caring for younger people might provide this support were discussed.

The psychosocial impact of breast cancer diagnosis and treatment amongst black and minority ethnic (BME) women in the UK.

Breast cancer is one of the most common forms of cancer in the UK. In 2005, more than 45,500 women were diagnosed with the disease (Cancer Research UK, 2008). With so many women developing breast cancer each year, it is the most common form of cancer in women of all ethnic groups (Breast Cancer Care, 2005).

The diagnosis and treatment of breast cancer can be a distressing experience for any individual. Research into this area has documented various adverse psychological and social consequences of breast cancer including depression (Burgess et al, 2005), distress (Simonton & Sherman, 1998), stigma (Harmer, 2006) and fear of death (Spencer et al, 1999). The treatment aspect of breast cancer also elicits concerns regarding one's body image and sexuality (Pelusi, 2006; Kinamore, 2008). Treatments such as chemotherapy, radiotherapy and adjuvant therapy come with adverse side effects such as hair loss, infertility, fatigue, weight gain/loss and menopausal symptoms. Furthermore surgical treatments such as mastectomy, lumpectomy or breast reconstruction can also impact upon a woman's self-image and not only challenge one's perceived levels of attractiveness but can also instigate femininity issues (Harmer, 2006).

While the conducted research adds to the current breast cancer literature, the majority of psychosocial research has been primarily focused on mainstream Caucasian women. There is very little work within the breast cancer literature that captures the experiences of Black and Minority Ethnic women (BME; Thompson et al, 2008). Studies that have looked at various ethnic groups (including BME and White women) show that while there are similarities in the women's experiences (e.g. recurrence of cancer and body image issues), there are also unique life experiences (e.g. cultural factors related to beliefs, gender role and family obligations) that also need to be addressed (Ashing-Giwa et al, 2004).

Therefore the aim of this research is to explore the psychosocial impact of breast cancer amongst South Asian and Black Caribbean women in the UK. In order to improve current understanding, this project will aim to capture these women's experiences of breast cancer including any body image and appearance related issues.

A series of studies will be undertaken:

Study 1

Will be an exploratory qualitative study involving Black Caribbean and South Asian women who have previously been diagnosed and treated for breast cancer.

Study 2

Will be guided from study 1 and a in-depth exploration of BME women's experiences of breast cancer, using a larger sample across the UK, will be sought.

Study 3

Will be a cross sectional quantitative survey of Caucasian, Black Caribbean and South Asian women with breast cancer. The study will be informed by the findings of studies 1 and 2 but likely issues for inclusion are psychosocial adjustment, perceptions and understanding of breast cancer, appearance related issues, provision of care and sources of support.

Study 4

Will be a national survey of healthcare professionals to examine their experiences of providing care for BME women with breast cancer.

For further information about any aspect of this study please contact Geeta Patel via email geeta.patel@uwe.ac.uk or call 0117 328 1895.

South Asian community views about individuals with visible differences

J. Hughes, H. Williamson, E. Williams, H. Naqvi, M. Johnson, R. Charlton and K. Saul on behalf of the Appearance Research Collaboration.

This research was supported by a grant to the Appearance Research Collaboration from The Healing Foundation.

Background

There is a paucity of research exploring the views of different cultural and ethnic groups concerning those with visible differences. As few standardised appearance measures have been translated, most appearance related research is therefore conducted in western cultures (USA and UK) with individuals who have a good command of the English language.

Conducting research in this area is a priority given that issues of disfigurement, stigma and shame may be particularly bound to membership of specific cultural and ethnic groups (Papadopoulos et al., 1999).

A recent case-study exploring British Bangladeshi living with a visible difference (neurofibromatosis, NF1), in a culture where social identity is inextricably linked to appearance and to judgements regarding marriageability (Rozario, 2007). Rohima's dark skin and lumps associated with her condition led her parents and relatives to regard her as unmarriageable and Bangladeshi men and women alike found her appearance a bar to any social acceptability. Three key themes relating to Bangladeshi cultural issues were identified: gender, sexual identity and marriage.

Aim

This paper aims to examine the views of UK South Asian communities towards individuals with visible differences.

References

Culley, L., Hudson, N., and Rapport, F. (2007) Using focus groups with minority ethnic communities: researching infertility in British South Asian Communities, *Qualitative Health Research*, 17: 102-112.

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Kent, G. (2000) Understanding the experiences of people with disfigurements: An integration of four models of social and psychological functioning. *Psychology, Health & Medicine*, 5 (2): 117-129.

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Rozario, S. (2007) Growing up and living with neurofibromatosis1 (NF1): a British Bangladeshi case-study, *Journal of Genetic Counselling*, 16(5):551-9.

Method

Sixty three participants from the West Midlands were recruited to 9 focus groups representing four South Asian communities: Indian (Gujarati) Hindu, Indian (Punjabi) Sikh, Bangladeshi Muslim and Pakistani Muslim. Groups were characterised by age, gender and ethnicity.

In order that questions and topics were culturally relevant, facilitators were chosen on the basis of their relevant language skills, gender and identification with and knowledge of the communities (Culley, Hudson and Rapport, 2007).

Discussions were held in the language of the group and translated into English for data analysis. Transcripts were analysed using template analysis (Kent, 2000).

Discussion

This paper offers a unique insight into views held by South Asian communities in the UK. A number of themes were identified which have been previously highlighted, in particular the impact of disfigurement upon social acceptability and marriage (Rozario, 2007).

Areas were identified that could inform interventions including education to dispel myths, raise awareness of sources of support and provide medical explanations for visible differences.

Focus group participants used the terms disfigurement and disability interchangeably suggesting that physical impairments may be regarded as highly salient visible differences and this may have implications for future interventions with these groups.

Limitations

The structured nature of the interview schedule may have presented little opportunity for participants to elaborate on view points. Furthermore, age groupings may not have reflected the country of birth of some participants.

Findings - Eight key themes were identified:

1. Definitions of and meanings attached to visible differences. There was also a misinformed association of visible difference with mental and physical disability

"you always make the assumption that they are not as capable as normal people"

2. Culturally specific myths and beliefs regarding the causation of visible differences were apparent.

"This was God's way of punishing you"

"The father along with the in-laws blame the mother"

3. The family's attitude towards and management of those with visible differences. Sense of burden and shame and evident impact on marriageability.

"parents would be worried about their child's marriage"

"we feel conscious about taking them into the public and being ridiculed, so for that reason we would not take them out much"

4. Social and emotional reactions to visible differences

"Some times we feel sorry for these people"
"We get shocked"

5. Social exposure of the person with a visible difference. A clear differentiation between an individual with a disfigurement being accepted in a religious gathering but not outside this context.

"Religious events will not affect them as much, in places like that people would be more sympathetic"

6. Cultural differences between South Asian and Western 'white' culture. Varied by generation.

"Their community (white) is more aware, exposed and educated about differences"

7. Medical intervention considered acceptable if for a medical reason but otherwise seen as against God/Allah's will. Character linked to physical appearance.

"It is a great sin to try to change the way of looks. Allah will punish them"

8. Sources of support. Immediate family was the main source. Lack of awareness of support services available and a sense of shame may limit access.

"some people don't want to go to the doctor because they are ashamed."





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Rumsey, N. (2008) The psychology of appearance: Why health psychologists should "do looks". *European Health Psychologist*, 10, 3, 46-50.

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In Press

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Malson, H. (in press) Appearing To Disappear: Postmodern Femininities And Self-Starved Subjectivities, in Malson, H. and Burns, M. (eds) *Critical Feminist Perspectives On Eating Dis/Orders*, Routledge, London



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Malson, H. (forthcoming) Qualitative methods from psychology, in R. Dingwall and I Bourgeault (eds) *The Sage handbook of qualitative methods in health research*, Sage, London

Tischner, I. and Malson H. (forthcoming) "You can't be supersized" – A discursive exploration of gender and body size, in E. Riches and L Monaghan, (eds) *Expanding the Obesity Debate*, Palgrave.



Conference Presentations and Talks

Appearance Research Collaboration (ARC) Symposium at Appearance Matters 3 conference, July 2008 (Bristol, UK).

Papers in the symposium:

- **Payne, E. & Williams, E.** & members of ARC (2008). Identifying factors and processes contributing to successful adjustment to disfiguring conditions in a community sample.

- **Clarke, S.A., Payne, E., James, H., Newell, R.J. & Thompson, A.R. & members of ARC** (2008). A qualitative investigation of change and stability in psychological adjustment to appearance.

- **Lindenmeyer, A. & members of ARC** (2008). The individual experience of coping with appearance: findings from a qualitative analysis of open-ended questions

- **Clarke, A. & members of ARC** (2008). Revisiting psychosocial interventions in visible difference.

Bellew, R presented "An exploration of the role of family processes and shame in adjustment of children with differences in appearance" at the UWE Psychology Postgraduate Conference (UWE, November 2008).

Bessell, A., Brough, V., Clarke, A., Harcourt, D., Moss, T., & Rumsey, N. Evaluation of a computer based psychosocial intervention for individuals with visible differences. Oral presentation at Appearance Matters 3 (Bristol, July 2008) and the joint DHP & EHPS conference (Bath, 2008)

Clarke, A., Payne, E. & Moss, T. The impact of appearance on intimacy: development of a new measure of intimacy. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Duggan, A., Clarke, V. & Halliwell, E. A qualitative exploration of the development of gay men's appearance beliefs and their implications for health related behaviours. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Dures, E 'The psychosocial impact of EB: the professionals' perspective'. She is also moderating the session 'Living with EB' in the psychosocial forum at the DebRA International 2008 conference (Mechelen, Belgium. October, 2008)

Egan, K (MSc Health Psychology student supervised by Di Harcourt) presented "A qualitative study of the experiences of people who identify themselves as having adjusted positively to a visible difference" at the UWE Psychology Postgraduate Conference (UWE, November 2008).

Fox, F., Morris, M. & Rumsey, N. Developing peer support groups online: the role of online groups for young people with chronic skin conditions. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Gibson F, Fox F & Williamson H. "What, yer want me to join yer study?" – The challenges facing researchers working with young people. Workshop at Appearance Matters 3 (Bristol, July 2008)

Harcourt, D gave a presentation titled "Using photography to explore adolescent experiences of appearance change during treatment for cancer" on behalf of Heidi Williamson, Emma Halliwell, Hannah Frith and Melissa Wallace at Teenagers and Young Adults with Cancer (TYAC) meeting (Manchester, December 2008).

Hayfield, N., Clarke, V. & Halliwell, E. A qualitative exploration of bisexual women's appearance and visual identity. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Hayfield, N., Clarke, V. & Halliwell, E. A qualitative exploration of bisexual women's appearance and visual identity. Oral presentation at BPS Psychology of Women's Section (POWS) Conference, (Windsor, July 2008)

Huxley, C., Clarke, V. & Halliwell, E. A qualitative exploration of lesbian women's appearance concerns. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Jackson, S., Rumsey, N. & Morris, M. Assessing the long-term benefits of corrective surgery in adults with eye misalignment (strabismus). Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Kennedy F, Harcourt D & Rumsey N. Perceptions of DCIS among UK health professionals. Oral presentation at the International Psycho-Oncology Society (IPOS) World Congress (Madrid, June 2008).

Kennedy F. presented: A longitudinal study of the psychosocial impact of a diagnosis of DCIS. British Psychosocial Oncology Society Conference (Leeds, December 2008).

Kennedy, F and Harcourt, D gave presentations on Fiona's DCIS PhD research funded by Breast Cancer Campaign during a site visit by the charity.

Rosser, B., Moss, T. & Rumsey, N. Are things as they appear? Information processing biases & appearance adjustment. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Rumsey, N. Satisfaction with facial appearance. CFSGBI annual conference (April 2008)

Rumsey, N. Psychological care for patients and families affected by burns. Invited address, British Burns Association. (Bristol, 2008)

Rumsey, N. 'Busting the Beauty Myths? Fact & Fiction in Appearance Research'. Keynote address at Appearance Matters 3 (Bristol, July 2008)

Rumsey, N. The Psychology of Appearance: Why Health Psychologists should 'do looks' Keynote address at the joint DHP & EHPS conference (Bath, Bristol, September 2008)

Rumsey, N. Is beauty in the eye of the beholder? Invited address at SciFest (St Louis, Missouri, October 2008)

Rumsey, N. Busting beauty myths: the impact of appearance in everyday life. Invited address at SciFest (St Louis, Missouri, October 2008)

Rumsey, N. Busting beauty myths: a users guide. Invited address at SciFest (St Louis, Missouri, October 2008)

Rumsey, N. Living with a Cleft. Keynote address at Scancleft. (Malmo, Sweden October, 2008)

Tischner, I., Malson, H., Rumsey, N. & Halliwell, E. "I just wear clothes to keep me warm and to stop people seeing my body" – Dressing the 'large' body. Oral presentation at Appearance Matters 3 (Bristol, July 2008)

Wallace, M. Harcourt, D. & Rumsey, N. Experiences of healthcare provision in adolescents with an altered appearance. Oral presentation at the joint DHP & EHPS conference (Bath, September 2008)

Williamson, H. Harcourt, D. Wallace, M. Frith, H. & Halliwell, E. Using photography as a tool for exploring young people's experiences of Appearance Change. Oral presentation at Teenage Cancer Trust Conference. (London, June 2008)

Poster presentations:

Clarke, S.A., **Payne, E.**, James, H., Newell, R.J. & Thompson, A.R. & **members of ARC.** A qualitative investigation of change and stability in psychological adjustment to appearance. Poster presented at the joint DHP & EHPS conference (Bath, September 2008)

Harcourt, D & Sherman K. Development & evaluation of an online decision aid to facilitate women's decision-making about breast reconstruction following mastectomy. Poster presented at Appearance Matters 3 Conference (Bristol, July 2008)

Hughes, J. **Williamson, H. Williams, E.** Naqvi, H, Johnson, M. Charlton, R & Saul K. South Asian community views about individuals with visible differences. Poster presented at Appearance Matters 3 Conference (Bristol, July 2008) & the joint DHP & EHPS conference (Bath, September 2008)

Jackson, S. Morris, M., Lilley, KT & Johnson AB. The psychological status of morbidly obese patients. Poster presented at Appearance Matters 3 Conference (Bristol, July 2008)

James, H., Newman, S., Shipley, M., Moore, S. & Olaleye, A. and **members of ARC** (2008). In the context of Rheumatoid Arthritis (RA) does appearance matter? Poster presented at Appearance Matters 3 conference (Bristol, July 2008)

Kennedy F, Harcourt D & Rumsey N. Discrepancies & challenges of ductal carcinoma in situ for health professionals. Poster presented at the Breast Cancer Campaign Scientific Conference (London, May 2008)

Kennedy F, Harcourt D & Rumsey N. Risk perceptions and communication of DCIS among UK health professionals. Poster presented at the joint DHP & EHPS conference (Bath, September 2008).

Kennedy F, Harcourt D & Rumsey N. A longitudinal study of the psychosocial impact of a diagnosis of DCIS. Poster presented at the NCRI Cancer Conference (Birmingham, October 2008).

Williamson, H, Harcourt, D. Frith, H. Halliwell, E & Wallace, M. Using photography as a tool for exploring adolescent experiences of appearance change during treatment for cancer. Poster presented at Teenage Cancer Trust Conference. (London, June 2008) & Appearance Matters 3 Conference (Bristol, July 2008)

Appearance Matters™ 4

A two day conference highlighting current research and good practice around appearance-related issues including visible difference, ethics, information provision, education, the media, resilience, identity, weight, provision of care, psychosocial interventions and areas for further research.

Hosted by
The Centre for Appearance Research
University of the West of England, Bristol

Date: **22 and 23 June 2010**
Venue: **Bristol, UK**

Keynote speakers include:

Professor Alex Clarke
Royal Free Hospital

The conference will be especially relevant to all researchers and clinicians interested in the psychosocial aspects of appearance, eg health, social, clinical and counselling psychologists, those working in health policy, surgery, nursing, medicine, health promotion, education, medical sociology and research students from all disciplines.

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