



Centre for Appearance Research

Supporting Families of People Affected by a Visible Difference Workshop

Delivered to members of the Appearance Collective
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Summary

Polite Notice

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Background to the workshop

Living with a visible difference can present a host of challenges, not just for those directly affected, but also for their families. While some families manage these challenges very well, others find them more difficult and may benefit from supportive interventions.

Workshop objectives

This interactive workshop explored different types of psychosocial intervention to support the families of people whose lives are affected by a visible difference. Using a stepped model of care, the workshop:

- Considered the issues that might prompt a need for support;
- Discussed the range of interventions currently available;
- Examined the role of research in intervention design and evaluation; and
- Invited attendees to input into the design of a new intervention to promote psychosocial wellbeing in families.

Activity 1: Common challenges

Delegates were asked to discuss the types of challenges that family members may experience.

The common challenges that the group identified included:

- Access to information
- Practical difficulties e.g. financial
- Isolation
- Feelings of guilt and anxiety
- Shock, trauma, stress responses
- Dealing with uncertainty
- Confidence
- Managing other people's reactions

- Unwanted attention
- Managing relationships with other members of the family (e.g. siblings, partners)
- Understanding treatment options
- Decision making in relation to treatment

Research summary

Challenges for families: What does the research say?

Families need to manage their own challenges, as well as support the child's psychosocial adjustment. Key challenges may include:

- Receiving a diagnosis / reactive distress to injury or acquired visible difference (Rey-Bellet & Hohlfield, 2004; Hall et al., 2006; Stock & Rumsey, 2015; Heath et al., 2018)
- Contact with non-specialist health professionals (Stock & Rumsey, 2015)
- Guilt or shame (Chamlin et al., 2004; Nelson et al., 2009; Baker et al., 2013; Hlongwa & Rispel, 2018)
- Changes to family life (Sank et al., 2003; Phillips, Fussell & Rumsey, 2007; Baker et al., 2009; Horridge et al., 2010)
- Attachment difficulties (Despars et al., 2011)
- Unwanted attention from members of the public / reactions from friends and family (Bradbury & Hewison, 1994; Johansson & Ringsbury, 2004; Rumsey & Harcourt, 2005)
- Social isolation (Tanner et al., 1998; Heath et al., 2018)
- Impact on wider family (including siblings) (Phillips, Rumsey & Fussell, 2007; Stock et al., 2016)
- Concerns about the child's future (Nelson et al., 2012)
- Ongoing burden of treatment (Nelson et al., 2012)
- Child experiencing teasing / bullying (Klein et al., 2006; Stock & Rumsey, 2015)
- Treatment decision-making (Nelson et al., 2012)
- Reduced overall quality of life (Razera et al., 2017)

Many families also report positive experiences (Eisermann, 2001; Johansson & Ringsberg, 2004; Klein, 2006), including:

- Increased empathy toward others
- Acceptance of life's ups and downs
- Greater adaptability to challenges
- Development of new knowledge or skills
- Closer familial relationships
- Rearranged priorities

Activity 2: Defining 'intervention'

The group defined 'intervention' as an action taken to intentionally become involved in a difficult situation in order to improve it or prevent it from getting worse (as in the Cambridge dictionary), but also to prevent a situation from becoming difficult in the first place.

Why do we need an evidence base for intervention?

- To find out what works, and if it works in the way we expected it to

- To be confident in what we're providing
- To know what works best for who
- To know what doesn't help
- To inform decision-making
- To avoid bias
- To avoid causing harm
- To assess cost-effectiveness
- To share experiences and learn from them

A good intervention is:

- Effective
- Cost-effective
- Accessible
- Available
- Acceptable
- Feasible
- Based on theory and research

It is important to be clear on the outcome you want to achieve from the outset, and to involve stakeholders throughout the process. A framework for developing and evaluating interventions has been suggested by the Medical Research Council:

<http://www.mrc.ac.uk/complexinterventionsguidance> (Craig et al., 2008).

The steps involve:

- Developing
- Piloting and feasibility
- Evaluating
- Reporting
- Implementing

There are also many challenges in intervention development. These include:

- Time
- Cost
- Recruitment
- Sample size
- Measurement
- Comparison group
- Pragmatics
- Misunderstanding about psychological support
- Ecological validity (also known as the 'science-practice gap')

Interventions can take many forms. CAR has developed a framework of interventions (in: Rumsey & Harcourt, 2012). This framework (Figure 1) is a representation of a stepped model of care, demonstrating a range of interventions that vary in terms of intensity and mode of delivery. At the base of the

triangle (level 0) are broad interventions aimed at promoting positive attitudes towards diversity of appearance across the general population as a whole. Moving up the triangle, interventions become more targeted and intense, and are likely to be needed by fewer people. Those at the top of the triangle (levels 4 and 5) are the most intense, for people with the most complex needs, and would typically be provided by an experienced psychosocial specialist such as a clinical psychologist.

Activity 3: Current intervention provision

The group was asked to discuss how their organisations currently help families to manage the challenges identified in Activity 1, and to place these interventions onto the CAR framework.

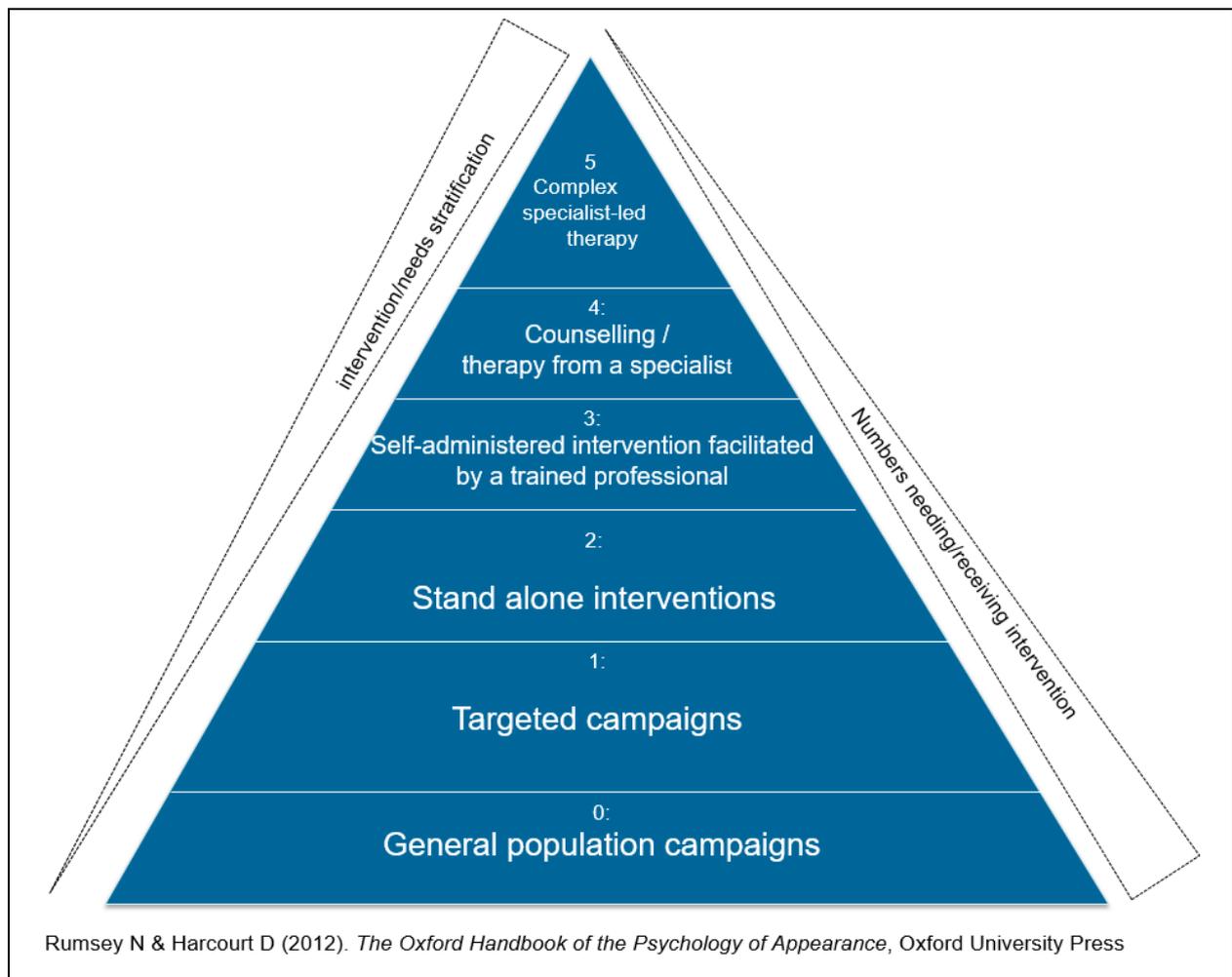


Figure 1: The CAR framework of interventions

Current interventions included:

- Awareness week activities
- Social media pages
- Online chats and forums
- Information and signposting
- Financial support
- Peer support
- Helplines
- Stress management
- Residential weekends and day events

The research process in practice: An example from burns research

Parents have different needs and emotional responses following their child's burn-injury. For these to be more adequately addressed, service users must be offered a range of information and support options following a stepped care model – with the best chance of delivering positive outcomes while burdening the user as little as possible. Service users and professionals must be consulted to ensure that the information presented is trustworthy, appropriate, and meets the needs identified.

Steps taken:

1. Identify the need (literature review, qualitative interviews)
2. Validate the findings in a larger sample (quantitative online survey)
3. Develop the intervention
4. Test the intervention by collecting stakeholder feedback
5. Disseminate the final product (academic papers, conferences, social media, press release)

Website launched: <http://supportingchildrenwithburns.co.uk>

Activity 4: Where to start?

The group were asked to discuss what type(s) of support they would prioritise for families, to think about how this support could best be delivered, and whether there is anything that should be avoided.

The priorities identified by the group included:

- Support in managing emotions
- Managing the reactions of other people
- Peer support
- Managing relationships with others
- Decision making
- Accessibility
- Education
- Normalising support and the need to access support

Additional Resources

- Bessell, A., & Moss, T. P. (2007). Evaluating the effectiveness of psychosocial interventions for individuals with visible differences: a systematic review of the empirical literature. *Body Image*, 4 (3), 227-238.
- Jenkinson, E., Williamson, H., Byron-Daniel, J. and Moss, T. (2015) Systematic review: Psychosocial interventions for children and young people with visible differences resulting from appearance altering conditions, injury or treatment effects. *Journal of Pediatric Psychology*, 40 (10). pp. 1017-1033.
- Muftin, Z. & Thompson, A.R. (2013). A systematic review of self-help for disfigurement: Effectiveness, usability, and acceptability. *Body Image*, 10, 4, 442-450.
- Norman, A. and Moss, T. (2015) Psychosocial interventions for adults with visible with differences: a systematic review. *PeerJ*, 3 (e870)

www.ypfaceit.co.uk
www.faceitonline.org.uk

Thank you

The CAR team would like to thank everyone who attended the workshop and the VTCTF for supporting the workshop series. The next workshop will be held in Spring 2019 and will focus on training others about visible difference. Further details will be available shortly.

Save the date!



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