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Brief research report

The provision of specialist psychosocial support for people with visible differences: A European survey

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ABSTRACT

A substantial body of research has demonstrated the challenges commonly facing people with visible differences (disfigurements) and explored the potential benefits offered by specialist psychosocial support and intervention for those who are negatively affected. However, little is known about the availability of such support in Europe for people whose appearance is in any way different to 'the norm'. This survey of 116 psychosocial specialists from 15 European countries, working with a range of patient groups, has shown a tendency for specialists to prioritise Cognitive-behavioural-based approaches, amongst a wide range of other approaches and interventional techniques. It indicates variations in the availability of support, and a perceived need for improved access to interventions, additional training, and greater awareness of the psychosocial issues associated with visible differences.

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1. Introduction

An estimated 10.2 million people in Europe have a visible difference (disfigurement) (M. Persson, personal communication, 27th July 2017), defined as looking different from what most would consider 'the norm' (Rumsey & Harcourt, 2012). This includes congenital (e.g., cleft lip/palate) and acquired conditions (e.g., psoriasis), or the consequences of trauma (e.g., burns) or biomedical treatments (e.g., surgical scarring). Irrespective of the type or aetiology of visible difference, challenges commonly experienced by those affected include dealing with the reactions of other people (including staring and unsolicited questions) and managing any negative impact on self-esteem and quality of life, in addition to social anxiety, avoidance behaviours, and depressive symptoms. These challenges have been documented by researchers (e.g., Feragen, 2012; Martin, Byrnes, McGarry, Rea, & Wood, 2017) and in personal accounts (e.g., Connolly, 2009; Partridge, 2006). Whilst many manage without needing high level support, others may benefit from interventions delivered by psychosocial specialists in this field (see Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014).

Funding from the European Cooperation of Science and Technology (COST) enabled a network for researchers and practitioners interested in appearance and body image (www.appearancematters.eu). Within this, we established a task group focussing on psychosocial interventions for visible differences, aiming to share expertise, promote intervention development, and identify best practice. This required a detailed understanding of available research evidence and service provision.

Systematic reviews conclude that cognitive behavioural therapy (CBT) and social interaction skills training dominate this field, and call for a broader repertoire of interventions to meet clients' needs (see Bessell & Moss, 2007; Jenkinson, Williamson, Byron-Daniel, &

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Moss, 2015; Muftin & Thompson, 2013; Norman & Moss, 2015). Since these reviews reflect only published and grey literatures, we also sought evidence of the support provided by psychosocial specialists working with patients and their families in practice.

Burn care is the only area where some, albeit limited, information exists. In 2001, a survey of staff providing psychological services to burns patients in 25 European countries was compared with data from the US, and found greater provision of support in the US than in Europe (Van Loey, Faber, & Taal, 2001). No significant differences were found between European countries. Half the European hospitals surveyed provided psychological services to less than 20% of burn inpatients, and less than 30% formally tested patients to identify those warranting support. Burn centres in Europe are now required to have a psychologist and social worker readily available (European Burns Association, 2017). A survey of 166 members of burn care teams in the US and UK (Lawrence, Qadri, Cadogan, & Harcourt, 2016) found UK teams were more likely to include psychologists, whereas social workers were more common in the US. Screening for distress was more common in the UK. CBT was the approach most commonly used by those identifying themselves as mental health practitioners, followed by acceptance and commitment therapy (ACT) or mindfulness.

While these surveys highlight support for people with burns, little is known about the provision for those with other conditions. To address this knowledge gap, we designed and conducted a survey to provide a holistic pan-European snapshot of current specialist support for people with visible differences, which could inform future research and clinical work. Specifically, we aimed to establish: (a) who provides specialist psychosocial support, in what context, and how is it accessed?; (b) how are clients' needs identified?; and (c) what interventions and approaches are currently being used? We also sought views regarding how care and research could be developed.

2. Method

The first author's institution granted ethics approval. The survey was created by members of the Clinical Interventions workgroup of the Appearance Matters COST Action (see above), informed by surveys in burn care (see Lawrence et al., 2016). The draft survey was amended following feedback from two clinicians, independent of the task group. Most questions were 'closed', with some open questions allowing respondents to expand on previous answers. At the outset, the group agreed that the target sample were likely to have a good understanding of English since their training and subsequent clinical work would involve academic papers and meetings conducted in English. Consequently, the survey was produced in English, but later translated into German and Portuguese in an attempt to increase responses. It was open to all psychosocial specialists in Europe self-identifying as working with clients with visible differences. Given the lack of any single over-arching European-wide organisation representing these specialists, our recruitment strategy was pragmatic, using snowballing to gather a large sample from as many countries as possible. The link to an online survey was disseminated via social media, and emails from the authors to relevant professional bodies (e.g., British Burn Association) and support organisations (e.g., European Cleft Organisation) who distributed it to their membership through emails and newsletters. It was also sent to the broader membership of the COST Action and the authors' own local and national contacts. Quantitative data was subjected to descriptive statistical analysis (SPSS for Windows, v20), and qualitative data to content analysis.

3. Results

The mean age of respondents ($N = 116$) was 42.5 years ($SD = 11.7$) and most were females ($n = 102$; 87.9%). Almost half were from the UK ($n = 53$, 45.7%), with others from the Netherlands ($n = 21$), Spain ($n = 6$), Norway ($n = 6$), Switzerland ($n = 6$), Austria ($n = 4$), Denmark ($n = 3$), Italy ($n = 3$), Ireland ($n = 2$), Portugal ($n = 2$), and one participant each from Belgium, Sweden, Bulgaria, Greece, and Poland. Five did not specify a country.

3.1. Who provides specialist psychosocial support, in what context, and how is it accessed?

Most respondents were qualified ($n = 73$, 62.9%) or trainee ($n = 6$; 5.2%) clinical psychologists. Others identified as health psychologists ($n = 5$; 4.3%), psychotherapists ($n = 13$; 11.2%), counsellors ($n = 11$; 9.7%), nurse specialists ($n = 7$; 6%), social workers ($n = 7$; 6%) or 'other' ($n = 8$; 6.9%). They worked across numerous specialties, mostly cleft lip/palate ($n = 36$; 31%), cancer ($n = 32$; 27.6%), and burns ($n = 29$; 25%). Some worked in multiple specialities, and most in more than one location, including hospital inpatient ($n = 76$; 65.5%) or outpatient ($n = 85$; 73.3%) settings funded by the state.

Most were part of a multidisciplinary team ($n = 103$; 88.8%). Many ($n = 43$; 36.5%) were the only psychosocial specialist in their team, whilst others worked with one ($n = 18$; 15.7%) or two ($n = 26$; 22.6%) others. Referrals came from specialist multidisciplinary teams (a reported mean of 39.7% of all referrals received), other specialties in general hospital/secondary care settings ($M = 24.7\%$), self-referral ($M = 15.8\%$), other sources ($M = 11.3\%$), and primary care/family doctors ($M = 10\%$).

3.2. How are clients' needs identified?

Almost one-third of respondents ($n = 35$; 31.3%) reported a structured approach towards psychological screening in their service (e.g., routinely using standardised questionnaires). Slightly fewer reported informal screening such as speaking to patients without using structured interviews ($n = 27$; 24.1%), or no routine screening ($n = 33$; 29.5%).

3.3. What interventions and approaches are used?

Respondents often worked with more than one age group (see Table 1), which explains why the total N (164) for this section is greater than the sample size. The most common reasons for referral across all age groups were: low self-esteem/confidence (reported by 137; 83.5%); body image/appearance concerns ($n = 134$; 81.7%); social anxiety/avoidance ($n = 125$; 76.2%); teasing, bullying, or staring ($n = 119$; 72.6%); and depression/low mood ($n = 119$; 72.6%).

More than half considered access to psychosocial support was easy in both inpatient (60%) and outpatient settings (56.7%); the remainder thought patients had difficulty accessing support in these settings. Various approaches and techniques were used (see Table 2), most frequently CBT ($n = 70$; 60.3%), psycho-education ($n = 60$; 51.7%), and mindfulness ($n = 47$; 40.5%).

Few participants used online or remote interventions ($n = 14$; 15.2%), the majority of which used telephone-based counselling ($n = 11$; 78.6%). Whilst the majority referred patients on to support elsewhere ($n = 71$; 77.2%), 10 of the 15 respondents who provided a reason for not referring on indicated suitable services were not available.

3.4. How do psychosocial specialists think care and research could be developed?

Only 48 respondents (38%) felt they had received sufficient training around interventions for people with a visible difference.

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