



# Factors associated with negative observer responses towards individuals with visible differences: A scoping review

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## ARTICLE INFO

### Article history:

Received 27 February 2017  
Received in revised form 14 February 2018  
Accepted 14 February 2018

### Keywords:

Visible differences  
Disfigurements  
Negative observer responses  
Scoping review

## ABSTRACT

People with visible differences are often confronted with negative observer responses, including stares, disgust, and avoidance. Characteristics of negative observer responses are well-documented, but less is known about associated factors. We conducted a scoping review to map what is known about factors associated with negative observer responses. Web of Science, PubMed, PsycINFO, and CINAHL databases were searched, and 16 articles met inclusion criteria. Two general categories of factors were identified: (1) observer characteristics, including age, sex, and socioeconomic status, experiences with disfigurements, and personal beliefs or attitudes related to visible differences; and (2) evolved internal mechanisms, including threat-detection, disgust, and disease avoidance. Additionally, there was evidence that lack of anonymity influences lower reporting of observer reactions. Efforts that increase exposure to individuals with visible differences may ameliorate adverse reactions; however, due to the limited nature of evidence reviewed, further research is needed before more concrete recommendations can be made.

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## 1. Introduction

Approximately one person in 100 has a visible difference (Changning Faces, 2016). Appearance-altering conditions that can lead to visible differences (Bessell, Dures, Semple, & Jackson, 2012) include congenital anomalies (e.g., cleft lip and palate, neurofibromatosis, birthmarks), acquired disfigurements from illnesses or

genetic conditions (e.g., acne, vitiligo), injuries (e.g., burns, accidents), and surgical interventions (e.g., treatment for head and neck cancer; Rumsey & Harcourt, 2004).

Whether present from birth or acquired later in life, visible differences are associated with substantial psychological and psychosocial impact (Clarke, Thompson, Jenkinson, Rumsey, & Newell, 2014; Rumsey & Harcourt, 2004), including negative body image, challenges with social interactions, as well as social anxiety and isolation (Clarke et al., 2014; Rumsey & Harcourt, 2004, 2012). Social anxiety may develop when experiences of exclusion or rejection lead to an ongoing fear of being evaluated negatively based on appearance (Baumeister & Leary, 1995; Kent, 2000). Thus, visible differences have been described as a form of social disability, because of their noticeability and potential to lead to negative reactions from others (Macgregor, 1990).

Examples of negative observer responses towards people with disfigurements include stares, startle reactions, whispered remarks, teasing, unsolicited questions, a lack of anonymity in social situations, advice, ridicule, disgust, and avoidance (Macgregor, 1990; Rumsey & Harcourt, 2004). Factors that contribute to negative observer responses have not been well-studied, although some explanations have been proposed, including the need for longer looking-times in order to process new information, the desire to avoid exposure to contagious disease, and emotional

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reactions such as disgust sensitivity and fear (Rumsey & Harcourt, 2004, 2012; Shanmugarajah, Gaiind, Clarke, & Butler, 2012).

Many studies have described the kinds of negative observer responses that are experienced by people with visible differences and their impact (e.g., Clarke et al., 2014; Macgregor, 1990; Rumsey & Harcourt, 2004). Fewer studies, however, have described factors associated with negative observer responses, including characteristics of people more likely to respond negatively to visible differences and other factors, such as beliefs and thoughts.

No reviews have mapped existing studies on the topic to describe key aspects that have been examined, identify research gaps, and describe the types of studies that are available and may be useful for the development of interventions and policies. A better understanding of factors that may contribute to negative observer responses would guide the design of further research on etiological aspects and inform psychosocial interventions aimed to help people living with visible differences cope with their unique circumstances. Policy-focused advocacy organizations, such as the UK-based not-for-profit Changing Faces, are increasingly focused on creating public policies and educational campaigns that seek to reduce discrimination and improve societal attitudes towards those with visible differences (Changing Faces, 2017); therefore, mapping factors associated with negative observer responses would aid in the development of recommendations towards these goals.

Thus, the objective of the present scoping review was to map existing evidence on the characteristics of observers and other factors associated with negative observer responses towards individuals with visible differences, including what is known from original empirical research, theoretical standpoints, and experiential perspectives.

## 2. Method

Scoping reviews are used to explore central concepts within a particular research domain that have not previously been reviewed comprehensively, including documenting the main sources and types of evidence available (Arksey & O'Malley, 2005). Scoping reviews follow a rigorous methodological framework similar to that of a systematic review; however, scoping reviews generally focus on broader questions, do not exclude studies based on design, and do not seek to evaluate the quality of included studies (Arksey & O'Malley, 2005). As recommended in guidelines on conducting scoping reviews (Arksey & O'Malley, 2005; Colquhoun et al., 2014; Levac, Colquhoun, & O'Brien, 2010), the present scoping review included six steps: (1) identifying the research question(s); (2) identifying relevant studies; (3) study selection; (4) charting the data; (5) collating, summarizing, and reporting the results; and (6) stakeholder consultation.

### 2.1. Identifying the research question

To guide the present scoping review, we defined the research question as: What characteristics of observers and other factors are associated with negative observer responses towards individuals with visible differences?

### 2.2. Identifying relevant studies

In order to identify potentially relevant articles that describe factors associated with negative observer responses towards people with visible differences, we searched Web of Science, PubMed, PsycINFO, and CINAHL databases from date of inception until July 10, 2017. A research librarian developed the search strategy and

performed the search. The complete search strategy is shown in the Supplementary Data File linked online to this article.

### 2.3. Study selection

Search results were downloaded into the citation manager Refworks (2009), and duplicate references were identified and removed. References were then uploaded into the systematic review software program DistillerSR (2015). Following this, we assessed the eligibility of each article in two stages. First, two investigators independently reviewed the titles and abstracts of articles that were identified through the search strategy. If either investigator deemed an article potentially eligible based on the inclusion criteria, the article was subsequently reviewed at the full-text level. Any disagreements regarding article inclusion after full-text review were resolved by consensus, and a third investigator was consulted when necessary. A bibliographic reference check and forward-citation search were completed for all articles included after full-text review, in order to identify any additional articles that were not identified by the database search. In addition, although review articles were not eligible, they were flagged, and reference lists were reviewed to identify any original research studies that met eligibility criteria.

Articles published in any language that reported on factors associated with negative observer responses towards people with visible differences were eligible for inclusion. There were no restrictions based on study methodology or article type. Visible differences were defined as conditions, whether congenital or acquired, that alter appearance in such a way that it is distinct from the perceived norm, whatever that may be (Rumsey & Harcourt, 2004). Studies that simulated visible differences to mimic congenital or acquired conditions were included. People whose appearance concerns directly relate to a psychiatric condition (e.g., body dysmorphic disorder) and those resulting from a physical disability (e.g., missing limb) were excluded (Rumsey & Harcourt, 2004). Negative observer responses were classified as any observable negative behavior or reaction towards an individual with a visible difference (e.g., staring; unwanted questions; avoidance; emotional expressions of disgust, repulsion, anger, anxiety, or embarrassment). Factors associated with negative observer responses included characteristics of the observers (e.g., age, sex, previous exposure to visible differences) as well as patterns of thinking and cognition, including theoretical models to explain negative responses (e.g., disgust-sensitivity, fear of contamination due to disease). Eligible studies had to report information on the observer or the experience of the observer. Thus, studies that described the experience of discrimination or stigmatization among individuals with visible differences, that described types of negative responses, or that described characteristics of individuals with visible differences associated with a greater likelihood of a negative response, for instance, but did not focus on the observer, were excluded. Articles that only mentioned factors associated with negative observer responses as part of introductory or discussion material, but that did not dedicate at least a section of the article to these reactions, were excluded. Articles were also excluded if they solely described negative observer responses towards individuals without a visible difference, such as people with physical disabilities (e.g., reduced mobility, amputations, loss of limbs, achondroplasia, or obesity).

### 2.4. Charting the data, and collating, summarizing, and reporting results

Two investigators independently extracted data from included articles and entered it into a standardized spreadsheet. For each publication, we extracted: (1) author information, publication year and location, and study design; (2) research question(s);

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