



Misrepresentation of ME/CFS in media images

A picture tells a thousand words What story are we telling?

The science: How does a photo tell a story?

We live in a world of information overload. Readers seek short cuts and tend not to read the detail. Without emotional investment people will not read detailed information.^{1,2}

An image can:

- capture attention^{1,3}
- convey and evoke emotions^{2,4,5}
- influence attitudes and beliefs³
- make the text easier to understand^{3,5}
- compress information^{3,5}
- freeze a moment in time^{2,4}
- share an idea and tell a story^{2,4,6}
- increase content retention⁵
- enhance retrieval from memory⁵
- reach all cultures and demographics

How quickly

In a glance at an image, the brain picks up the story between 6 and 600 times faster than language.^{1,2,7}

How effectively

- Novel or unusual information attracts attention. Unique photos will be more effective than stock photos.⁸
- The brain filters out most incoming data. Compared to text, images are more likely to be retained.⁸
- While an image cannot replace the specificity of words, an image can trigger memory retrieval of the associated text.²

What are the wrong stories ?



Hallmann 2021, unpublished: Of 298 articles in Google News, the majority of inappropriate photos portrayed fatigue or depression.¹⁴



Photographs that misrepresent lived experience have the power to impede understanding in ways that impact on clinical guidance, research funding and support for patients with ME/CFS.

Viewers trust the veracity of the message contained in the selected image. The wrong image creates a false narrative that anchors misinformation, influencing the way the text is read.^{9,10} Visuals that are inconsistent with the content, can override the story in the text.^{11,12} Visuals that confirm misinformation in the text will amplify the message.^{12,13}

At its least harmful, choosing generic stock photos to simply decorate the text, loses the opportunity to tell a meaningful story.²

In a Google News search of ME/CFS and CFS, 60% of images showed a person in office wear with a hand on the head.¹⁴

It could be inferred from popular stock images in use, that people with ME/CFS typically:

- work in an office
- have an upright posture, showing muscle strength, balance and ability to remain vertical
- are able to complete normal Activities of Daily Living (ADLs), e.g. dressing, grooming
- have symptoms of discomfort, fatigue/tiredness and pain, which are everyday experiences for healthy people.
- have a mild illness
- have little or no disability
- have ordered, minimalist surroundings without assistive technology, support people or everyday essentials within arm's reach

Symbolic violence¹⁵

The impact of these misrepresentations includes:

- euphemisation
- delegitimisation
- invisibilisation
- non-recognition

Conclusion

Time and effort to select appropriate images is warranted, given the power of images to either reinforce bias and stigma, or to accurately represent the illness and invoke an emotional and concrete investment in research funding, clinical guidance and support for people with ME/CFS.⁹

Countering decades of epistemic injustice requires persistent and consistent use of both images and words that capture the reality of lived experience.

Why does it matter ?



When the severity and complexity of ME/CFS are trivialised:

- government agencies and philanthropists have **no reason** to prioritise research funding
- clinicians have **no reason** to seek education
- the public and thus politicians have **no reason** to engage
- patients remain marginalised.¹⁶

Realism

Language often directs the choice of image. Centering 'fatigue' in the name of the illness, the diagnostic criteria, and the clinician-patient dialogue, undermines recognition of the unique characteristics of post-exertional malaise and the complexity of the illness. In the same way, using photos of healthy people, pretending to be tired, reinforces a decades-long misconception.^{12,17}

Representation

Photographs that have been staged to represent weariness, headache and depression reinforce the psychologisation of ME/CFS, colluding with false-illness belief and deconditioning tropes.^{9,12} Over time, this has marginalised research based on pathophysiology, led to acceptance of harmful treatment recommendations, and fuelled paradigms that support abuse such as psychiatric detention and child removal.^{16,18}

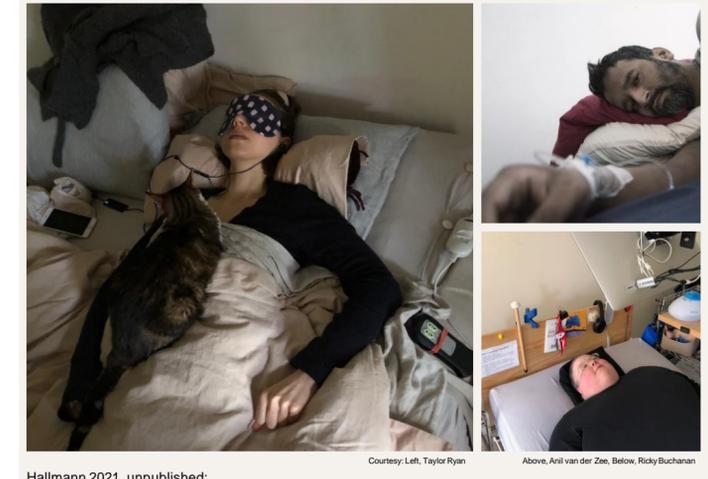
When the illness is consistently represented by Caucasian office workers, ME/CFS diagnosis is made less likely for ethnic minorities, lower socio-economic groups, children and teenagers.¹⁹

Even when choosing to use a photograph of a person who has ME/CFS, capturing the wrong moment can misrepresent a person's life.⁶

Ideology

Images can encode ideology, including the values, beliefs and attitudes that drive decision-making across all domains.¹⁷

What can we do?



Hallmann 2021, unpublished: Of 298 articles found in Google News, only 17 had a realistic image of a person with ME/CFS.¹⁴



The power of an image warrants input from the author of the accompanying text, to ensure that the image complements the text.¹⁰

An image can encapsulate an entire story. A photo that freezes the right moment in time can bring that story to the intended audience in a way that anchors and amplifies the purpose of your text.¹²

Choosing the right photo

For an honest and accurate portrayal of the severity, complexity or seriousness of the illness, give consideration to:

Appearance

- posture
- muscle tone
- facial pallor
- clothing
- grooming

Setting

- lived environment⁴
- elements that bring relevant detail to the story, e.g. everyday necessities within arm's reach

Demographics

- age
- gender
- race
- ethnicity
- family structure

Focus

- framing the photograph to draw attention to the most salient element⁶
- captions that add context and assist understanding⁴

Stills from Unrest (2017)



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