

Title

Dementia: beyond disorders of mood

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Word count

1628

Keywords

dementia; emotion; mood; depression; anxiety

Funding source

The article was produced as part of S Petty's PhD studentship at the University of Nottingham, funded by The Retreat, York. The funding source did not determine the content or the decision to submit the article for publication.

Disclosure of Interest

The authors report no conflicts of interest.

Acknowledgements

Author's Contributions: S Petty affirms that everyone who contributed significantly to the work has been listed as an author. The authors wish to thank The Retreat, York for their generous support.

EDITORIAL

Dementia: beyond disorders of mood

This editorial will present the growing argument in the research literature that mood disorders, as defined by psychiatric diagnostic criteria, do not well serve individuals with dementia. This is important because anxiety and depression are our most used and most influential ways of understanding a highly prevalent and personally important experience in dementia: emotion. As such, there is a need to review how the disorders are currently conceptualised (American Psychiatric Association, 2013) since they may have limited applicability for individuals with dementia, and consider what alternatives there might be. Agitation is offered as a lesson in how imprecise descriptions of behaviour can exclude the internal world of people with dementia. In our research to explore how the emotional experiences of individuals with dementia are understood (Petty, Denning, Griffiths & Coleston, 2016), we consider what might lie beyond disorders of mood.

Constrained by mood disorders

The first reason why mood disorders are ill-fitted for individuals with dementia is the difficulty differentiating mood from other experiences of dementia. This is due to the sometimes shared descriptions of behaviour, such as ‘loss of interest’ or ‘apathy’ as inclusion criteria for depression (Verhey & Visser, 2000; Robert et al. 2009), and ‘difficulty concentrating’ as a component of anxiety (Seignourel, Kunik, Snow, Wilson & Stanley, 2008), despite there being different possible meanings and causes. Apathy, for instance, may be a feature of a depressive disorder, but it has a distinct clinical and biological profile, and furthermore, appears to have subtypes with different neural substrates (Levy and Dubois, 2006).

Individuals with dementia might also show depressed mood in ways that do not apply for the wider population (Verhey & Visser, 2000). This overlap of symptom descriptions then causes difficulties when attempting to design instruments that can accurately assess mood symptoms and detect changes in mood (Spector et al. 2015; van der Linde et al. 2016). This has led to recommendations for revised criteria for some mood disorders for individuals with dementia (Starkstein, Jorge, Petracca & Robinson, 2007). The Cornell Scale for Depression in Dementia (CSDD) (Alexopoulos, Abrams, Young & Shamoian, 1988) is a well-regarded measure that attempts to address these concerns. Even so, it remains to be agreed as to what the CSDD is measuring (Barca et al. 2015; Kirkham et al. 2016). And despite these intended improvements, measures that attempt to separate mood from other experiences in dementia are not the most widely used (van der Linde et al. 2016).

Second, aside from the possible need for distinct descriptions of mood for individuals with dementia and individuals without dementia, there is an argument that mood disorders as experienced with mild dementia do not equate to those experienced with more advanced dementia, and do not require the same interventions (Mintzer, Brawman-Mintzer, Mirski & Barkin, 2000). It is worth restating the comments of Verhey and Visser (2000), that dementia does not impact people in a uniform way, though this is often an implicit assumption of researchers. Because of the variable impact and severity of dementia, there is difficulty applying mood criteria for all individuals with dementia in a valid way (Seignourel et al. 2008).

A third problem with applying mood disorder diagnoses is the difficulty diagnosing depression or anxiety when individuals are not able to communicate their thoughts and feelings. In such circumstances, concepts such as having confidence in yourself or describing the things that cause you worry can only be assessed using symptom checklists and are then inferred from overt behaviour (Verhey & Visser, 2000; Seignourel et al. 2008). For this

reason, some authors have suggested that interventions designed to alleviate negative mood cannot be evaluated well because it is not easy to be sure whether meaningful change in the person's mental state has occurred (Ford & Almeida, 2015).

Fourth, the widely variable experiences of anxiety and depression make uniform boundaries around these mood disorders difficult to maintain (Mintzer et al. 2000; Verhey & Visser, 2000; Seignourel et al. 2008; van der Linde et al. 2016). There is an unresolved overlap of descriptions of depression and apathy, for example (Robert et al. 2009; Seignourel et al. 2008). And mood symptoms such as apathy and elation have received less research attention than anxiety and depression, meaning their boundaries are less well established (American Psychiatric Association, 2013; van der Linde et al. 2016).

Finally, the prevailing understanding of emotion in dementia, as reflected in the research literature, is that mood is a symptom of dementia or is a symptom associated with dementia (Mintzer et al. 2000; van der Linde et al. 2016). However, determining whether dementia directly causes mood disorders is 'exceedingly difficult' (Seignourel et al. 2008, p. 3). Also predominant is the notion that anxiety and depression cause distress (Verhey & Visser, 2000; Ford & Almeida, 2015; Qazi, Gutzmann & Gul, 2017). This can be an unquestioned assumption, whereby dementia causes mood to be disordered, which then inflicts emotional distress. An alternative understanding when referring to individuals with dementia is that emotional distress is experienced for a wide variety of reasons relating to the experience of dementia, and this is labelled as anxiety or depression. This second understanding is embedded within emotion-orientated interventions for dementia (Finnema et al. 2000; Brooker & Latham, 2015).

Thus, there is reason to be cautious about relying upon a person's outward behaviour to infer their internal experiences. This is especially true when the best available means of

conceptualising a wide range of behaviours is with two predominant mood disorders. The prevalence of mood disorders, then, is part of a broader pattern.

Agitation as a lesson

Agitation is perhaps the most misunderstood symptom of dementia, if indeed it is a symptom. Agitation has the definition of being an observed behaviour, of an unbounded list of behavioural descriptions, without an explanation (Cohen-Mansfield & Billig, 1986). The most-used assessment measures of agitation include, amongst other items: hitting and kicking, screaming, appearing upset, trying to get to a different place, resisting care interventions, hiding things or requesting attention or help (Cohen-Mansfield, 1986; Cummings et al. 1994; van der Linde et al. 2016). Implicit in these descriptions is the idea that there is some form of emotional distress underlying the motor behaviour, but this distress is shadowy, ill-defined, and rarely understood. Agitation is a phenomenon that is observed but not understood; when the behaviour is considered to be unwarranted, or without link to a known need of the person, 'agitation' is considered to be an appropriate term. Thus agitation is an umbrella term, a description of indiscriminate behaviours, that, by its definition, does not portray the person's internal world; it is a means of seeing only the external.

'Neither the concept of agitation nor its etiology is clarified in the literature,' (Cohen-Mansfield & Billig, 1986).

The confusion around agitation and what it essentially corresponds to means it is indiscriminately equated with other behavioural descriptions, including depression and anxiety (Starkstein et al. 2007; Seignourel et al. 2008; Robert et al. 2009; Livingston et al. 2014). And as with the mood disorders, agitation is often considered to be a direct symptom

of dementia by default (Livingston et al. 2014). Agitation is not a symptom of dementia.

Agitation is not a mood disorder. Agitation does not equate to emotional distress.

Over time, we have seen a shift in how agitation is defined, from it being regarded as inappropriate, pointless, activity that did not reflect the needs of a person, to a view of agitation as behaviour that arises from misunderstood or unmet needs (e.g. Livingston et al., 2014). This reformulation owes much to authors such as Brooker, Snape, Johnson, Ward and Payne (1997), Woods (1999) and Cohen-Mansfield (2000). The unmet needs might include ‘emotional comfort or communication’ (Livingston et al. 2014, p. 441). Thus, going forward, ‘agitation’ should be used as a flag for further understanding, including curiosity towards the internal world of the person.

There is a lesson for us to be learning from the way in which ‘agitation’ has become an over-used short-hand to talk about people with dementia. It may be that anxiety, depression and agitation as behavioural descriptions each overlap, and fall beneath a single syndrome (Seignourel et al. 2008). This one syndrome might be a more accurate, all be it less directing, starting point from which to be curious about emotional distress.

Alternatives to disorders

The uncertain validity of mood disorders has implications for how the experience of emotions for individuals with dementia is understood and how people respond to them. This includes the design and evaluation of pharmacological and non-pharmacological interventions for negative mood (Orgeta, Qazi, Spector & Orrell, 2015; van der Linde et al. 2016).

Interventions that have been most evaluated address discrete mood disorders (Spector et al. 2015) and even these are relatively under-researched (Ford & Almeida, 2015); when anxiety

and depression are considered to be mood disorders, there has not yet been a satisfactory approach to alleviating the symptoms (Orgeta et al. 2015; Ford & Almeida, 2015). The labels have high face validity with clinicians, but when talking of validity, we need, as a starting point, to know what is intended to be measured. If by valid we mean a strong and truthful measure of emotional distress, the mood disorder labels fall short, are unstable and imprecise.

Considering this growing caution over the usefulness of mood disorder diagnoses in dementia, it is worth exploring alternatives. Alongside the ongoing investigations into the applicability of mood disorder criteria, future research should consider personal accounts of distressing emotions for individuals with dementia, so as to understand this phenomenology in more depth. Examples of existing research into the personal experience of people with dementia, which include accounts of the emotions experienced, are by Clare, Rowlands, Bruce, Surr and Downs (2008) and Steeman (2013). Alternative conceptualisation of emotions as personal, continuous, widely variable and co-occurring is worth exploration. Better conceptualisation of emotion in dementia, phenomenological research approaches and ‘person-centred’ interventions have each been requested (Verhey & Visser, 2000; Seignourel et al. 2008; Qazi et al. 2017). When considering the clinical care of any individual, clinicians should tread cautiously when holding the current descriptions of mood disorders to be valid and true, rather, they might be a best-now but limited solution. More broadly, a new wave of research is welcome, which looks between and around the mood disorders to see what might otherwise exist. These recommendations would be aligned with psychological theories into the commonplace experience of emotions for individuals with dementia (Magai et al, 1996; Miesen, 1999; Davenhill, 2007; Evans, 2008; Brooker, Dröes & Evans, 2017) and the emerging evidence of the personal accounts of emotional distress for people with dementia (Swaffer, 2016; Bartlett, Windemuth-Wolfson, Oliver & Denning, 2017). The recommendations would also be aligned with aspirations to engage meaningfully, in a

relationship with individuals with dementia as people: persons with personhood (Kitwood, 1997; Brooker, 2004).

Conclusion

The exploration of alternatives to mood disorders is not new but continues to evolve. This brief editorial cannot capture the wealth of research conducted in this area to date or celebrate it adequately. But the general approach to describing and understanding the emotions of people who have dementia is constrained within two or three labels. This is unfortunate as it overlooks the richness and complexity of their experiences. What might be possible is greater movement towards widely variable and personally meaningful descriptions of emotional distress, and better understanding of what causes the range of emotions and individualised responses. Emotion is an important part of the internal world of people with dementia, and seems to exist beyond the disorders of mood.

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