Moving from hopeless to hopeful: Understanding the experiences of adults in midlife living with anorexia nervosa

Leslie A. McCallum

University of Toronto, Canada

Anorexia nervosa (AN) is a complex, life-threatening mental illness with high comorbidity rates. This disorder has one of the worst prognoses of all mental illnesses, with a mortality rate of 10.5%. It affects people of varying socioeconomic statuses, cultures, sexes, genders, and ages. There is no universally effective treatment for adults living with AN. Despite the high percentage of individuals who continue to live with AN for decades, there is limited understanding of what it means to be in midlife living with a disorder that is more commonly noted to occur among adolescents and young adults. This was a qualitative study using constructivist grounded theory methodology. This research was conducted in accordance with the ethics protocol approved by the Health Sciences Research Ethics Board of the University of Toronto. Nineteen individuals in midlife (40 to 65 years of age) living with AN participated in individual, in-depth interviews. Four main findings emerged from this study. First, important differences exist between livings with AN in midlife versus when one is younger. Second, based on this sample and their retrospective accounts, complex trauma is common among individuals in midlife living with AN. Third, midlife can act as a barrier to seeking treatment and/or facilitate disengaging from treatment. Fourth, shifts occur in midlife that can act as catalysts to fully engaging in recovery. Honoring the added challenges that come with midlife, as well as harnessing qualities developed in midlife will help this older age group move forward with their recovery journey, moving from feeling hopeless to feeling hopeful.

Anorexia nervosa is a disease in which the individual maintains a low weight as a result of a pre-occupation with body weight, construe either as a fear of fatness or pursuit of thinness. In anorexia nervosa, weight is maintained at least 15 per cent below that expected, or in adults body mass index (BMI) – intended as weight in kilograms divided by height in metres squared – is below 17.5 kg/m2. In younger people, the diagnosis may be made in those who fail to gain weight during the anticipated growth spurt of puberty, as they can become underweight without weight loss.

Weight loss in anorexia nervosa is induced by avoiding ‘fattening foods’, sometimes supported by excessive exercising or self-induced purging (by vomiting or misuse of laxatives). As a consequence of poor nutrition, a widespread endocrine disorder involving the hypothalamic-pituitary-gonadal axis develops, manifest in women by amenorrhoea and in men by a lack of sexual interest or potency. In prepubertal children, puberty is delayed and growth and physical development are usually stunted.

The subjective experience of anorexia nervosa is often at odds with the assessment of others. The conviction that weight control is attractive is usually strongly held, mainly when challenged and others are seen as false in believing the person should gain weight, mainly where there is a marked disturbance of body image. Weight loss is experienced as a positive achievement and, therefore, may be strongly reinforcing to someone with low confidence and poor self-esteem. As a result, they will frequently deny the significance of the condition. The necessary role of ‘weight phobia’ is increasingly being questioned however, and is believed by some to be culture specific.

The condition generally starts with dieting behaviour that may evoke no concern. Indeed, some will experience reinforcing compliments. After a while, however, the commitment to dieting increases, often with a number of secondary features such as social withdrawal, rigidity and obsessionality, particularly where these traits have previously been features of the person’s personality. A number of secondary difficulties may develop including physical adverse effects, social isolation, compromise of educational and employment plans and occupation in the areas of leisure, self-care, daily living and productivity of employment and/or education. A smaller number will enter anorexia nervosa through a pattern of purging behaviour without dieting, following a viral illness, which resulted in weight loss that then became positively valued, or in the context of a chronic illness such as diabetes or Crohn’s disease.

The diagnosis of anorexia nervosa in its typical form is a relatively straightforward one in older adolescents and adults. The diagnosis has good validity and reliability, the main obstacle to diagnosis being the person’s own willingness or otherwise to disclose his or her motives, symptoms and behaviours. Thus, engagement in a supportive, empathic assessment interview is crucial in enabling the person to reveal fears around weight, dieting behaviour and any purging or other maladaptive behaviour such as excessive exercising.

This work is partly presented from Global Summit on Neurology and Neurosurgery on January 16-17, 2020 at Lisbon, Portugal

In the absence of this engagement, the individual may fail to reveal weight-controlling behaviours and collude with the doctor in pursuing physical investigations to explain the weight loss. In women, the presence of secondary amenorrhoea (i.e. cessation of menstruation after it has been established) or other physical features of starvation should always alert the physician to the possibility of this diagnosis.

The diagnosis is made on the basis of the history, supported where possible by a corroborative account from a relative or friend. Physical examination, with measurement of weight and height and calculation of body mass index (BMI), can reveal the extent of emaciation. On occasion, clinical observation during a hospital assessment can enable characteristic behaviours to be observed. Physical investigations are less useful in making the diagnosis but are crucial in assessing the physical impact of the disorder and its complications. Depending on the results of the physical examination, these may include haematological tests, electrocardiography, radiological assessment and ultrasound. The extent to which the family and/or next of kin need to be involved in treatment relates to age and developmental issues, the severity of the illness and the risk of harm.

This work is partly presented from Global Summit on Neurology and Neurosurgery on January 16-17, 2020 at Lisbon, Portugal