



NEDC
Members Meeting
Pathways Through Care

What does the research say about the care experience through the system?



BJPsych Open (2019)
5, e59, 1–10. doi: 10.1192/bjo.2019.48

Review

Current eating disorder healthcare services – the perspectives and experiences of individuals with eating disorders, their families and health professionals: systematic review and thematic synthesis

Gemma Johns, Bridget Taylor, Ann John and Jacinta Tan

Background

Eating disorders have the highest mortality rate of mental disorders and a high incidence of morbidity, but if diagnosed and treated promptly individuals can benefit from full recovery. However, there are numerous problems at the healthcare interface (i.e. primary and secondary care) for eating disorders. It is important to examine these to facilitate appropriate, seamless treatment and improve access to specialist care.

Aims

To examine the current literature on the experiences and perspectives of those across healthcare interfaces for eating disorders, to include individuals with eating disorders, people close to or caring for those with eating disorders such as family and friends, and health professionals.

Method

To identify relevant papers, a systematic search of electronic databases was conducted. Other methods, including hand-searching, scanning reference lists and internet resources were also used. Papers that met inclusion criteria were analysed using a systematic methodology and synthesised using an interpretative thematic approach.

Results

Sixty-three papers met the inclusion criteria. The methodological quality was relatively good. The included papers were of both qualitative ($n = 44$) and quantitative studies ($n = 24$) and were from ten different countries. By synthesising the literature of

these papers, three dominant themes were identified, with additional subthemes. These included: 'the help-seeking process at primary care'; 'expectations of care and appropriate referrals' and 'opposition and collaboration in the treatment of and recovery from eating disorders'.

Conclusions

This review identifies both facilitators and barriers in eating disorder healthcare, from the perspectives of those experiencing the interface first hand. The review provides recommendations for future research and practice.

Declaration of interest

None.

Keywords

Eating disorders; healthcare interface; patients and carers; systematic review; thematic synthesis.

Copyright and usage

© The Royal College of Psychiatrists 2019. This is an Open Access article, distributed under the terms of the Creative Commons Attribution-NonCommercial-NoDerivatives licence (<http://creativecommons.org/licenses/by-nc-nd/4.0/>), which permits non-commercial re-use, distribution, and reproduction in any medium, provided the original work is unaltered and is properly cited. The written permission of Cambridge University Press must be obtained for commercial re-use or in order to create a derivative work.

Background and rationale for review

Eating disorders are relatively rare but are associated with a multitude of physiological, psychological, social and economical complications and have the highest mortality of all mental disorders.^{1–3} Evidence suggests that prompt diagnosis and early intervention improves recovery prospects.⁴ However, eating disorders are difficult to diagnose and treat.^{3,5}

with eating disorders may be left untreated, facing long waiting lists, inappropriate referrals and prolonged illness, exacerbating eating disorders and decreasing the likelihood of recovery.⁹

In the UK, up to 1.25 million people are affected by eating disorders, yet there are relatively scarce resources available to treat them.^{10,11} The National Health Service (NHS) proposes to deliver better healthcare based on 'principles and values'.

Primary Care

- primary care services described as an ‘obstacle’ or ‘barrier’ to care, rather than the first port of call or ‘gate-keepers’
- lack of experience, understanding and knowledge, particularly among GPs and practice nurses
- lacked time and resources to diagnose and treat also ‘uninterested’ in eating disorders believing it is simply a matter of ‘just eating’ or focused on physical symptoms of an eating disorders
- even in severe cases, long waiting lists and a lack of resources with no guarantee of admission and treatment
- Carers feeling ‘fobbed off’
- Helpseeking a ‘long arduous journey’ by family

The Healthcare Interface

- Healthcare is generally a partnership between the individual with eating disorders, family/friends and professionals.
- For eating disorders this partnership is often marred by hostility, opposition and power relations.
- Oppositions between physical and emotional aspects of eating disorders can result in power relations affecting partnerships
- With power, there is control (or loss of) resulting in mutual mistrust and other ramifications.
- A better collaborative understanding of eating disorders across the primary–secondary interface is needed, so all partnerships are on the same page.

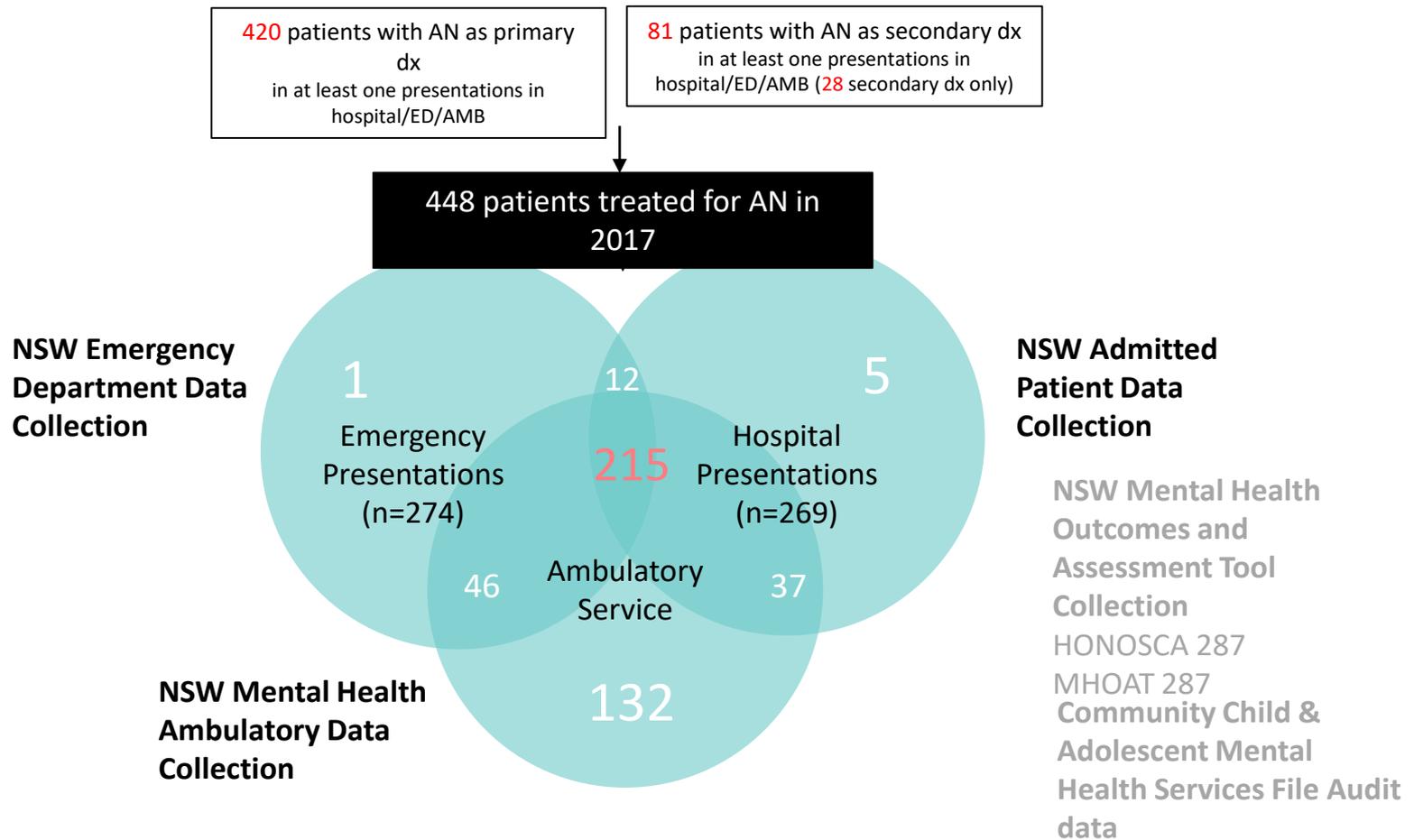
Ideal Characteristics of Care

- Trustworthy and can build a strong therapeutic relationship
- respectful and empathic
- available and consistent
- Understanding, knowledge and experience of eating disorders
- Ideal setting for treatment is safe and supportive environment – somewhere
- that feels ‘like home’
- considers the individual as a ‘whole person’
- offers a ‘collaborative’ approach to treatment
- ‘individualised and client-focused’
- ‘good professional’ needed to remain authoritative, reflecting confidence and professionalism
- set meaningful and appropriate treatment goals

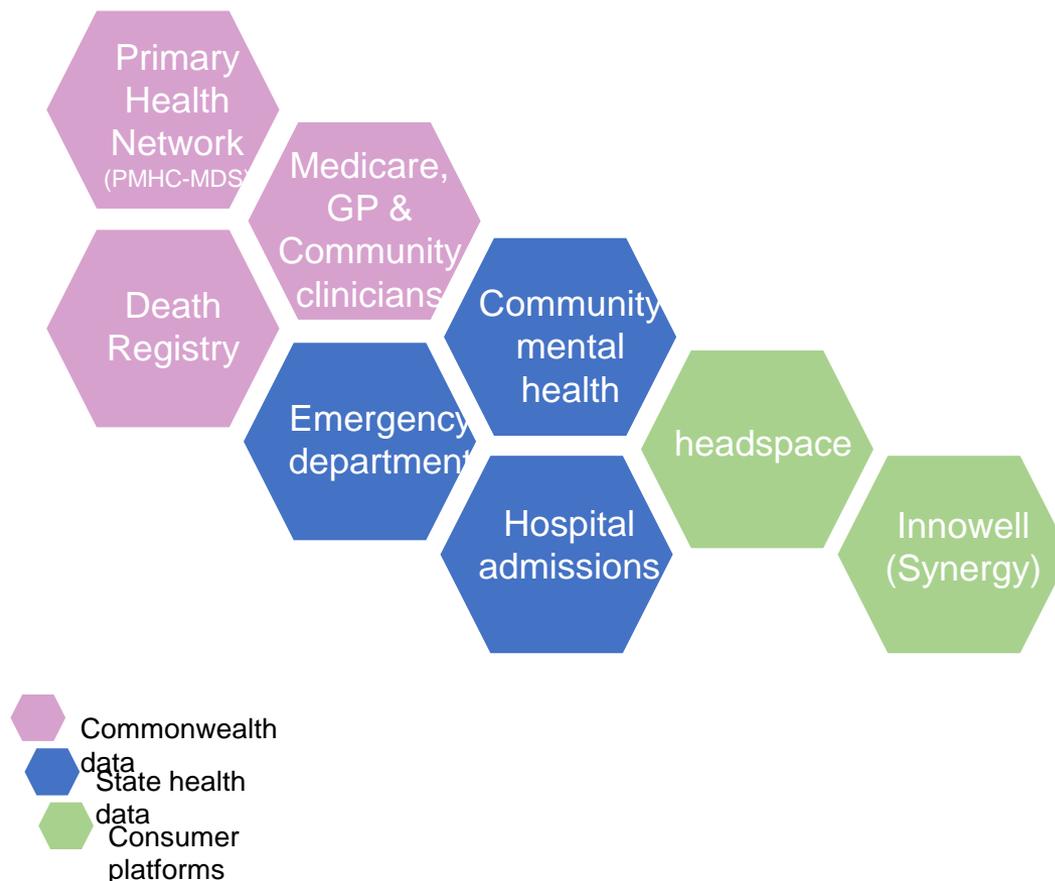
InsideOut's response

- Hopefully multi-faceted
- Co-design in everything we do
- Lived experience on staff working across streams
- Health Service Reform with heavy focus on pathways
- Health system research – are people accessing care
- Evaluation and research of the user experience, pathway research – PROMS PREMS mandatory
- National Research and Translation Strategy with 'heavy' co-design and consultation focus
- Listen, be accountable, take criticism, in fact be very curious to criticism
- Place the client at centre of care experience

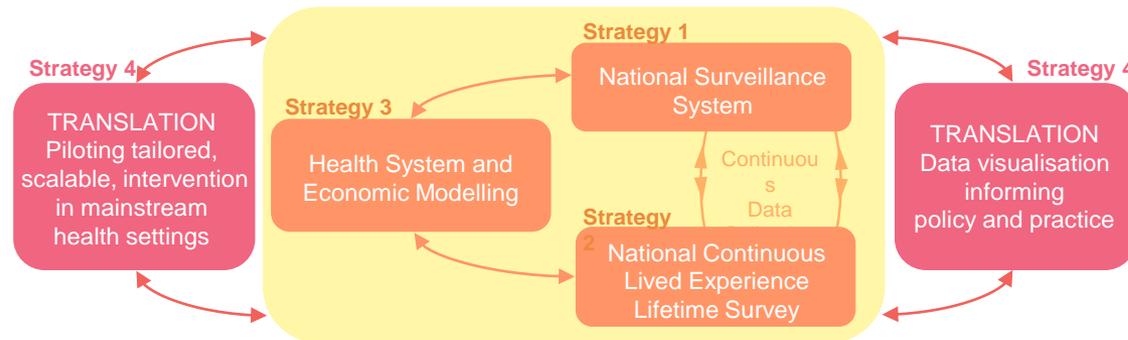
Study Cohort



Million Minds: Building a National Surveillance System for Detection and Intervention of Eating Disorders



Million Minds: Building a National Surveillance System of Detection and Intervention for Eating Disorders



What could we be doing?