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## 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.

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## 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.<sup>1–3</sup> Evidence suggests that prompt diagnosis and early intervention improves recovery prospects.<sup>4</sup> However, eating disorders are difficult to diagnose and treat.<sup>3,5</sup>

Generally, healthcare is regarded as a partnership between patients and professionals. For eating disorders, however, this relationship can be ambivalent, with inconsistencies in healthcare.<sup>6,7</sup> Primary care (i.e. community-based generalist medical care) is usually the first port of call for any health-related complaint and the setting where many conditions are diagnosed and managed. Some disorders may require specialised treatment and transitions or co-management across the interface between primary and secondary (i.e. specialist) care. The coordination between different levels of care can be fraught.<sup>6</sup> For example, family physicians/general practitioners (GPs) often feel unequipped to identify and manage eating disorders and prefer to pass care to specialist services.<sup>8</sup> However, specialist services are often significantly under-resourced, overburdened and unable to accept high numbers of referrals. As a result, patients

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.<sup>9</sup>

In the UK, up to 1.25 million people are affected by eating disorders, yet there are relatively scarce resources available to treat them.<sup>10,11</sup> The National Health Service (NHS) proposes to deliver better healthcare based on 'principles and values'. English, Welsh and Scottish NHS healthcare systems all espouse principles and values for better integrated service for all patients with patient-centred, shared decision-making and better inter-agency working.<sup>12,13,14</sup>

Despite variation, healthcare has many similarities internationally.<sup>6</sup> Most healthcare systems face challenges of rising cost and increasing demand as quality of care improves,<sup>15</sup> with many governments committed to improving primary–secondary transitions.<sup>16</sup> Several countries successfully use similar principles and values to the UK. In New Zealand and the USA, shared partnerships and shared responsibility in treatment in distributing resources more efficiently have improved health outcomes. In the USA, more investment in primary care has successfully shifted care to out-patient clinics. In Sweden, patient-centred care is prioritised –

looking at healthcare through the ‘patient’s eyes’ and in the Netherlands, ‘neighbourhood care’ is optimised.<sup>15</sup>

Given the commonality of these challenges across different healthcare systems, it is important to review the current literature on eating disorder health provision at the primary–secondary care interface at an international level, to explore the facilitators and barriers existing in eating disorder healthcare, and then draw conclusions that can underpin recommendations to ensure eating disorders are diagnosed and treated in line with principles of good clinical practice.

## Aims and objectives

The aim of this paper was to systematically review and thematically synthesise the current literature on the primary and secondary care healthcare interface for eating disorders. These included a range of perspectives and experiences of: individuals with eating disorders; people close to individuals with eating disorders, such as family members, loved ones and close friends; and health professionals working with eating disorders. This review was conducted to gain a better understanding and a more comprehensive account of the healthcare interface for eating disorders. To do this, data was collected from mixed methods primary studies to assess and understand a range of different experiences and perspectives and examine the facilitators to and barriers of eating disorder healthcare to provide recommendations for improvements in future research and practice.

The research questions we asked were: (a) what are the current facilitators and barriers across primary and secondary eating disorder healthcare services; and (b) what conclusions can be drawn from the international literature to improve the healthcare services for eating disorders?

## Method

### Search strategy and selection criteria

This systematic review was performed according to the Preferred Reporting Items for Systematic Reviews by PRISMA 2009 Checklist.<sup>17</sup> Studies were considered for inclusion for the review if they met the predetermined study eligibility checklist shown in Appendix 1. A comprehensive search of electronic databases was conducted in May to September 2017. These databases were: Web of Science, PubMed, APA PsychNET, PsycINFO, CINAHL, SCOPUS, Science Direct and Social Sciences Citation Index. No restrictions were placed on geographic location or publication date. However, language and methodological filters were applied to ensure that studies were restricted to the English language only, and study designs were primary studies only. In addition, searches also included hand-searching, scanning of reference lists and searching internet resources. All databases and other resources were searched using a combination of search keywords and terms. These included keywords relating to population groups (for example ‘patients’, ‘sufferers’, ‘people with an eating disorder’, ‘service user’, ‘family’, ‘carer’, ‘loved one’; ‘health professionals’, ‘primary’, ‘secondary’ and so on); types of eating disorders (for example ‘anorexia nervosa’, ‘bulimia nervosa’, ‘binge-eating disorder’ and so on); and types of treatment settings (for example ‘in-patient’, ‘out-patient’, ‘primary’, ‘community’, ‘GP practice’). Each search term was adapted for individual databases or other resource types as needed, matching them against titles, abstracts and subject descriptors.

### Data extraction and synthesis

The retrieved studies were screened for relevance and rated against the inclusion/exclusion criteria for further consideration by two

reviewers (G.J. and J.T.) using a stepwise approach, for example screening for titles and abstracts. Eligible studies were then obtained in full-text and reviewed. Data were extracted using a data extraction form developed by the reviewers. The extracted data included: study characteristics and design, lived experiences and personal perspectives of outcomes.

To analyse the data, studies were synthesised and interpreted using a qualitative narrative synthesis methodology that integrates and compares findings, by looking for themes or constructs across individual studies.<sup>18</sup> This process comprised using the extracted data from all three population groups, which were then subcategorised using a thematic approach to the data to identify emerging themes, to enable exploration of people’s perceptions and experiences. An interpretivist approach was applied to this synthesis to deepen understanding of the findings across the papers and go beyond the original findings to generate new constructs and explanations.<sup>19</sup> To do this, the data was extracted and coded, that is, data was read line-by-line, and relevant data was categorised into list-form, under specific headings and subheadings. This created descriptive themes of the data, then similar codes from each additional paper were grouped together to synthesise the data in to a more analytical format to construct themes, from which dominant themes and subthemes were then created. These themes were drawn from similarities identified in the data and matched across the three participant groups. Each identified category, heading/subheading and descriptive themes, and their analytical format were double-checked and double-coded, and any discrepancies were then discussed and resolved. This process was conducted by two of the authors (G.J. and J.T.).

## Quality assessment

The studies were assessed by one author (G.J.) and a proportion (20%) of these were additionally double-coded by another (J.T.). Any discrepancies were then discussed and resolved. This was assessed using an adapted version of the Critical Appraisal Skills Programme checklist for both qualitative research and randomised controlled trials.<sup>20</sup> The checklist consisted of four subscales (10 items) reporting: aims, methods, design, recruitment, data collection, bias, ethics, analysis/testing, findings/conclusions, and value. The highest possible score was 20. A ‘good’ rating score for each subitem was allocated a score of ‘2’, ‘fair’, ‘1’ and ‘poor’, ‘0’. The cut-off threshold for inclusion was set relatively low (score >10) as this is a review of perspectives and experiences, not of effectiveness or quality.

## Results

An initial scope of the electronic databases and the internet (such as Google scholar and Google) generated a total of 1480 papers. Of these, 1362 papers were excluded after reading the titles and abstracts, as not meeting full criteria. The remaining 118 papers were retrieved in full, after which, a further 20 papers were excluded. A data extraction and quality assessment of the remaining 98 papers was conducted, resulting in 35 papers being excluded. In total, 63 papers met the inclusion criteria for the review.<sup>21–83</sup> Table 1 provides the quality assessment scoring of the 63 selected papers and Fig. 1 provides an overview of the selection process as a flow diagram.

### Methodological quality and study characteristics

The quality of the included papers was considered to be good to fair. All these papers were rated highly for design, methodology, recruitment, analysis and overall value. Therefore, all 63 papers were considered of an appropriate quality for inclusion in this review.

**Table 1** Quality assessment score

Author	Date	Score (out of 20)
Tierney <sup>21</sup>	2008	19
Rie <i>et al.</i> <sup>22</sup>	2006	18
Clinton <i>et al.</i> <sup>23</sup>	2014	17
Linville <i>et al.</i> <sup>24</sup>	2012	19
Robinson <i>et al.</i> <sup>25</sup>	2012	18
Bravender <i>et al.</i> <sup>26</sup>	2016	18
Sheridan & McArdle <sup>27</sup>	2016	19
Boughtwood & Halse <sup>28</sup>	2010	19
van Ommen <i>J et al.</i> <sup>29</sup>	2009	19
Rosenvinge & Klusmeier <sup>30</sup>	2000	17
Reid <i>et al.</i> <sup>31</sup>	2008	19
Gulliksen <i>et al.</i> <sup>32</sup>	2015	19
Gulliksen <i>et al.</i> <sup>33</sup>	2012	19
Nilsson & Hagglof <sup>34</sup>	2006	19
Zugai <i>et al.</i> <sup>35</sup>	2013	19
Federici & Kaplan <sup>36</sup>	2008	17
Fox & Diab <sup>37</sup>	2015	18
Smith <i>et al.</i> <sup>38</sup>	2016	18
Escobar-Koch <i>et al.</i> <sup>39</sup>	2010	18
Swain-Campbell <i>et al.</i> <sup>40</sup>	2001	19
Dimitropoulos <i>et al.</i> <sup>41</sup>	2015	19
Pettersen & Rosenvinge <sup>42</sup>	2002	19
Grange & Gelman <sup>43</sup>	1998	18
Lindstedt <i>et al.</i> <sup>44</sup>	2015	18
Walker & Lloyd <sup>45</sup>	2011	19
Paulson-Karlsson & Nevenon <sup>46</sup>	2012	18
Colton & Pistrang <sup>47</sup>	2004	19
Zaitsoff <i>et al.</i> <sup>48</sup>	2016	19
Offord <i>et al.</i> <sup>49</sup>	2006	19
Rance <i>et al.</i> <sup>50</sup>	2015	18
Clinton <i>et al.</i> <sup>51</sup>	2004	19
Schoen <i>et al.</i> <sup>52</sup>	2012	19
Evans <i>et al.</i> <sup>53</sup>	2011	19
Halvorsen & Heyerdah <sup>54</sup>	2007	19
Roots <i>et al.</i> <sup>55</sup>	2009	19
McMaster <i>et al.</i> <sup>56</sup>	2004	19
Winn <i>et al.</i> <sup>57</sup>	2004	19
McCormack & McCann <sup>58</sup>	2015	19
Honey <i>et al.</i> <sup>59</sup>	2008	19
Tierney <sup>60</sup>	2005	19
Cohn <sup>61</sup>	2005	18
Haigh & Treasure <sup>62</sup>	2003	18
Reid <i>et al.</i> <sup>63</sup>	2010	19
Currin <i>et al.</i> <sup>64</sup>	2009	19
Bannatyne & Stapleton <sup>65</sup>	2016	19
Burket & Schramm <sup>66</sup>	1995	19
Boule & McSherry <sup>67</sup>	2002	19
King & Turner <sup>68</sup>	2000	17
Linville <i>et al.</i> <sup>69</sup>	2010	19
Linville <i>et al.</i> <sup>70</sup>	2012	19
Walker & Lloyd <sup>71</sup>	2011	19
Vanderlinden <i>et al.</i> <sup>72</sup>	2007	19
Jones <i>et al.</i> <sup>73</sup>	2013	19
Masson <i>et al.</i> <sup>74</sup>	2009	19
Johnston <i>et al.</i> <sup>75</sup>	2007	19
Anderson <i>et al.</i> <sup>76</sup>	2016	18
Banas <i>et al.</i> <sup>77</sup>	2013	19
Johansson <i>et al.</i> <sup>78</sup>	2015	19
Ramjam <sup>79</sup>	2004	18
Girz <i>et al.</i> <sup>80</sup>	2014	19
Hay <i>et al.</i> <sup>81</sup>	2007	19
Ryan <i>et al.</i> <sup>82</sup>	2006	19
Hunt & Churchill <sup>83</sup>	2013	19

The included papers consisted of qualitative methodologies ( $n = 44$ ), including semi-structured/in-depth interviews or focus groups and quantitative methodologies ( $n = 24$ ) using questionnaires or online essays (63 papers in total, but some had mixed-method approaches –  $n = 68$  methodologies). Of the included

papers, the sample size varied substantially, ranging between 5 to 1522 participants. The samples were a mix of ages and genders. The included papers were published between the years 1995 and 2016. The studies were conducted across a range of geographic locations, including the UK and Ireland ( $n = 20$ ), USA and Canada ( $n = 18$ ), Australia and New Zealand ( $n = 13$ ), Sweden and Norway ( $n = 11$ ), and Netherlands and Belgium ( $n = 2$ ). The population groups of these studies included individuals with eating disorders across a range of eating disorder types and severities ( $n = 37$ ), family/friends ( $n = 10$ ) and health professionals ( $n = 21$ ).

The settings of the included papers of individuals with eating disorders and family/friends were ‘in-patient’ (child, adolescent, adult, eating disorders and mental health) ( $n = 17$ ), drop-in specialist eating disorder centres ( $n = 2$ ), university centres ( $n = 1$ ), out-patient ( $n = 8$ ), community recruitment/in home settings ( $n = 8$ ), general medical wards/hospital ( $n = 4$ ), private practice ( $n = 1$ ) or online resources ( $n = 1$ ).

For health professionals, the reported occupations/settings included: specialist eating disorder clinicians, medical doctors and nurses (GP practice, general ward, paediatric, mental health), psychiatrists, psychologists, dietitians, obstetricians, gynaecologists, counsellors, therapists (psychiatric, occupational), social workers, health visitors, midwives, dentists and student/fellow/resident health professionals. The characteristics for each paper are outlined in supplementary Table 1 (available at <https://doi.org/10.1192/bjo.2019.48>).

## Summary of thematic analysis

By gathering the data and comparing the types of perspectives and experiences, three dominant themes emerged from the synthesis of the studies to allow for similarities and disparities to emerge and provide a comprehensive insight into the functions and barriers of the healthcare interface for eating disorders. The dominant themes and the subthemes are outlined in detail below. Appendices 2–4 provide a summary of each theme.

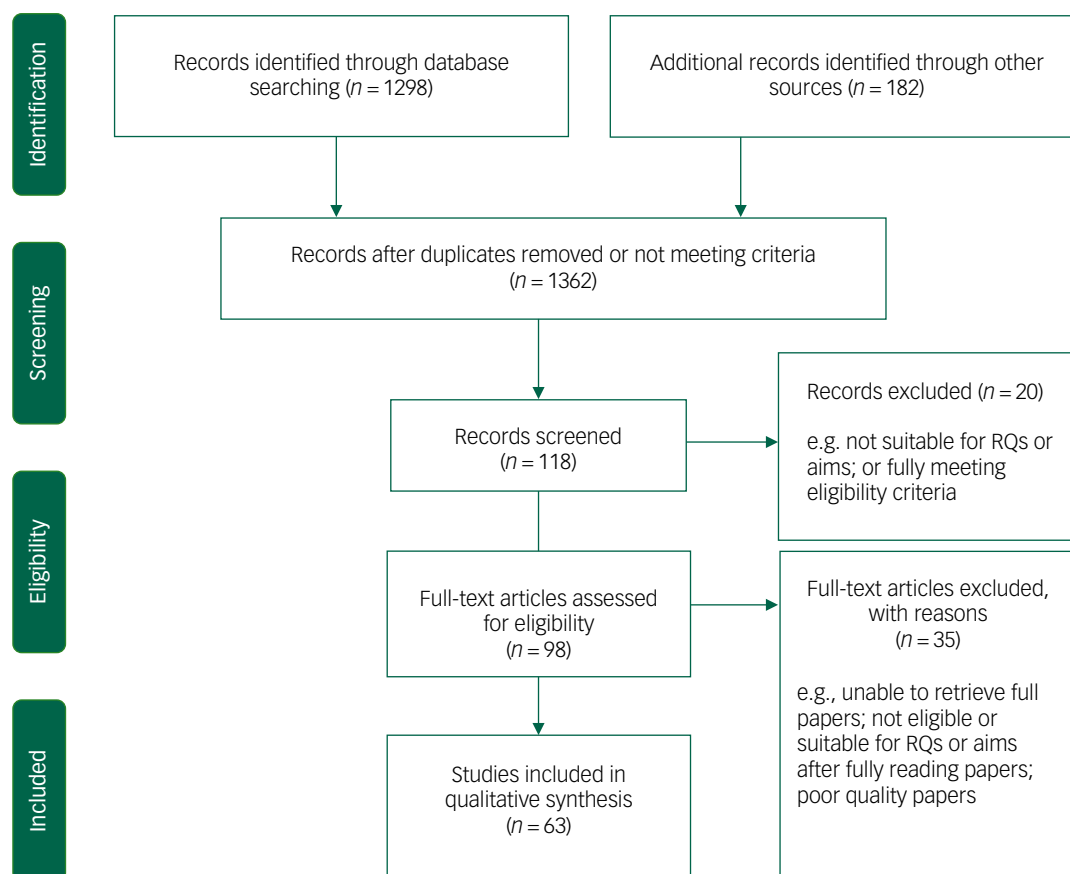
### Theme 1: the help-seeking process

The first dominant theme that emerged from the literature is the help-seeking process and the primary care setting. This entails two subthemes and describes the process of individuals with eating disorders and family/friends of those with eating disorders seeking professional help in primary care settings, and the professional role of the primary health professionals in this process.

#### Subtheme 1: the help-seeking process at its current state

Individuals with eating disorders’ perspective of barriers to care and unhelpful experiences

In the literature, individuals with eating disorders considered primary healthcare the most appropriate and opportunistic setting to diagnose eating disorders and intervene in the first instance.<sup>1,10,12,24</sup> Identified primary healthcare professionals included a GP/family physician or primary practice nurse,<sup>1,2,10,12,24,32,33</sup> social worker,<sup>1,33</sup> dietician,<sup>33</sup> counsellor or psychologist.<sup>1,10,12,33</sup> However, the health professionals in primary care settings were reported as presenting challenges and difficulties at the early stages of help-seeking. Individuals with eating disorders reported lack of eating disorder experience, understanding and knowledge among primary care professionals, particularly among GPs, practice nurses and social workers.<sup>1,2,5,10,12,19,21,25</sup> Furthermore, frequent failure to detect eating disorder symptoms and provide a timely diagnosis was described.<sup>1,19</sup> For individuals with eating disorders, primary care professionals not only lacked time and resources<sup>5,30</sup> to diagnose and treat



**Fig. 1** Flow diagram of selection of papers.

RQs, (a) What are the current facilitators and barriers across primary and secondary eating disorder healthcare services? (b) What conclusions can be drawn from the international literature to improve the healthcare services for eating disorders?

eating disorders, but were also ‘uninterested’ in eating disorders, believing it is simply a matter of ‘just eating’,<sup>25</sup> or focused on physical symptoms of an eating disorders.<sup>19,25</sup> In consequence, diagnosis of an eating disorders often only occurred when physical symptoms became severe and pronounced.<sup>1,19,25</sup> However, even in severe cases, long waiting lists and a lack of resources with no guarantee of admission and treatment by more specialised services for eating disorders were major barriers.<sup>1,2,5,19,21,25,30</sup> For individuals with eating disorders, the primary care service was described as an ‘obstacle’ or ‘barrier’<sup>1,19,33</sup> to care, rather than the first port of call or effective ‘gate-keepers’ to specialist services.<sup>19</sup>

#### Family/friends’ perspective of barriers to care and unhelpful experiences

Likewise, for family/friends of individuals with eating disorders, help-seeking was initially sought in primary care or community settings such as GP practices and schools,<sup>36,37,38,42</sup> but self-help books, internet resources, support-based organisations or private treatment were where most of the ‘useful help’ was located.<sup>36,37</sup> For some family/friends, primary health professionals were helpful<sup>37,38,39,40</sup> in terms of providing ‘active support’, without blame or judgement.<sup>38</sup> Some described ‘thorough and competent’ primary care professionals.<sup>39</sup> However, others found primary care a negative experience,<sup>38</sup> feeling ‘fobbed off’.<sup>40</sup> They reported that primary care professionals lacked eating disorder knowledge<sup>37,38,39</sup> and the training required to diagnose and respond to eating disorders.<sup>42</sup> They did not provide clear advice<sup>39</sup> or provide essential management of eating

disorders.<sup>37,42</sup> Knowledge of available treatment options<sup>37,38</sup> and the ability to negotiate with other healthcare systems to get access to referrals was poor.<sup>36,37,38,42</sup> This caused ‘frustration and anger’<sup>38</sup> and ‘resentment’ towards the professionals.<sup>36</sup> The process of help-seeking was described as a ‘long arduous journey’ by family/friends,<sup>36</sup> and some described how their own resourcefulness and inexhaustible search for help ultimately helped the person with an eating disorder obtain the treatment they need – which is about being ‘not prepared to give up’ and do ‘whatever is necessary to aid recovery’.<sup>36</sup>

#### Healthcare professionals’ perspective of barriers to care and unhelpful experiences

Professionals in primary care settings (for example GP practices, general wards, student/resident placements) described their professional role regarding eating disorders as a ‘double-bind’.<sup>63</sup> They faced challenges and difficulties with individuals with eating disorders, their families and the eating disorder healthcare interface itself. Primary care professionals argued that individuals with eating disorders are difficult and challenging<sup>63</sup> and create tension between all parties.<sup>63</sup> They felt that people with eating disorders often lack motivation and adherence with treatment, with much of the drive for help-seeking and recovery coming from the families.<sup>43,46,47,48,49,63</sup> Therefore, some primary care professionals were reluctant to work with eating disorders,<sup>51</sup> with expressions of ‘frustration’,<sup>46,48</sup> ‘resentment’<sup>45</sup> and ‘irritability and disgust’ in the physical comorbidities,<sup>45,47</sup> considering eating disorders as

being 'low prestige' compared with other illnesses,<sup>45</sup> with some stating they 'don't like' or 'don't want to work with them'.<sup>46,56</sup> Other primary care professionals indicated that they just 'don't', or 'don't want' to screen for eating disorders,<sup>46,49,55,57</sup> as they find them time consuming or too complex,<sup>43,46,47,49,50,51</sup> or just preferred to diagnose eating disorders rather than manage their care and treatment.<sup>47,53,60</sup> Yet others were frustrated they 'can't work' with eating disorders,<sup>43,45</sup> expressing a wish to be trained in eating disorders, because their role in detecting eating disorders symptoms was important.<sup>55,57</sup>

Primary care professionals saw the lack of training and resources in eating disorders as a barrier<sup>43</sup> and felt that frustration caused negative attitudes that then impeded therapeutic relationships.<sup>43</sup> It was widely recommended that a well-validated universal screening protocol for eating disorders would build confidence in primary care settings.<sup>49,50,53,55</sup>

Primary care professionals insisted that the challenges of working with eating disorders and professional negative attitudes were associated with 'clinical' problems<sup>44</sup> such as feeling unequipped to diagnose and intervene with eating disorders<sup>50,57</sup> because of a lack of eating disorder experience,<sup>43,65,56,58,63</sup> knowledge/understanding,<sup>43,44,49,56</sup> and adequate training and skills.<sup>43,45,47,49,50,51,60</sup> They identified larger-scale 'organisational' problems<sup>51</sup> that eating disorders are considered specialist disorders and requiring specialised care.<sup>43</sup> However, they recognised that specialist care referrals are often unavailable or unobtainable,<sup>43,47,49</sup> thus, primary care professionals were faced with challenges of trying to make referrals to inaccessible specialist treatment.<sup>49,55,63</sup>

### Subtheme 2: utilising the primary care setting

In the literature, individuals with eating disorders suggested that the early stages of contact with a primary care professional needs to be a 'positive experience'<sup>12</sup> and this is greatly influenced by two factors. First, they expected sufficient knowledge of eating disorders and good interpersonal skills among primary care professionals.<sup>12</sup> Second, they expected sensitivity regarding eating disorder 'control'.<sup>1,12,14,32</sup> For individuals with eating disorders, anxiety, ambivalence and resistance to treatment and/or help-seeking are often grounded in a fear of 'losing personal control'.<sup>12,32</sup> Because individuals with eating disorders often approached help-seeking with mixed feelings and motives, they felt that the professionals should emphasise 'facilitating positive reactions', encouraging individuals with eating disorders to speak openly rather than attempting to change behaviours and fix the eating disorder.<sup>12,32,41</sup> This would allow individuals with eating disorders to feel they are in good hands, yet 'feel safe and listened to'<sup>12</sup> and able to sustain some personal control and the ability to take responsibility for their own actions.<sup>12,14,41</sup> For individuals with eating disorders, this was a crucial point early in the help-seeking, which was necessary to enable them to be ready to change and seek recovery – a 'testing the waters'<sup>32</sup> or a tentative 'action stage' in eating disorder treatment.<sup>12,14,16,22,24</sup> Being an active agent throughout treatment and into recovery was described in the literature as 'turning points' and success stories were described as 'internal motivation' or 'want(ing)' help,<sup>1,4,16,22,23,27,54</sup> which depended greatly on 'timing' and being in the right place at the right time.<sup>12,22,24</sup> Therefore, a therapeutic approach was crucial at earlier stages of help-seeking in primary care, because if 'positive perceptions at help-seeking are formed as a result of this initial attempt, then future treatments were more effective in altering disordered eating behaviours'.<sup>32</sup>

Despite difficulties, studies suggested efforts were needed to better utilise the primary care setting as an opportunity to encourage the 'action' stage from individuals with eating disorders by

providing supportive and therapeutic relationships<sup>14,16,22</sup> and offering a sense of safety, commitment and validation<sup>11</sup> while maintaining a mutual relationship among all parties as mutual 'agents of change'.<sup>36,41</sup> Primary care professionals could potentially help turn the first highly ambivalent consultation into a positive experience or successful turning point.<sup>12</sup> A successful first encounter at primary care was described as a potential 'powerful catalyst' enable further treatment of and recovery from eating disorders.<sup>14</sup> Appendix 2 outlines the key points from theme 1.

## Theme 2: expectations of care and appropriate referrals

The second dominant theme is the 'expectations of care and appropriate referrals'. This theme entails two subthemes. This looks at the 'ideal', and the functions and barriers surrounding the assumed 'best' eating disorder service.

### Ideal characteristics of care and treatment

Individuals with eating disorders and their family/friends said 'one professional' could make a real difference in eating disorder care and treatment.<sup>54</sup> This 'good' professional, regardless of whether they belonged to primary or secondary care services, was characterised as someone they can trust,<sup>27,30</sup> and build a strong therapeutic relationship with,<sup>7,15,22,24,25,28,33</sup> who is respectful and empathic.<sup>1,2,5,7,11,13,15,17,18,19,22,25,33,41</sup> This 'good professional' needed to be available and consistent<sup>7,13,15,22</sup> and have a sufficient understanding,<sup>5,11,12,13,18,19,21,23,33</sup> knowledge and experience of eating disorders.<sup>1,8,9,12,13,22,25,26</sup> The ideal setting for this treatment to take place was in a safe and supportive environment – somewhere that feels 'like home',<sup>7,11,13,15,21,22,23,27,28,29</sup> considers the individual with eating disorders as a 'whole person',<sup>7,18,19,29</sup> and offers a 'collaborative' approach to treatment,<sup>7,18,19,21,24,26,27,29,33,41</sup> that is 'individualised and client-focused'<sup>18,19,21,29</sup> offering consultative and directional care.<sup>9,11,33</sup>

At the same time, the 'good professional' needed to remain authoritative, reflecting confidence and professionalism<sup>13</sup> and setting meaningful and appropriate treatment goals.<sup>17,28</sup> It is suggested that a combination of 'autonomy and direction' equals 'balance and success' in eating disorder treatment.<sup>11</sup> Some professionals also supported this ideal system, suggesting that although eating disorder experience, skill and knowledge are important in the treatment of eating disorders, building strong relationships with individuals with eating disorders and their family/friends, and delivering care holistically can have a greater impact of helpfulness than any type of treatment provided.<sup>43,59,61,62</sup>

### Specialised and/or complex? – So, who's responsible for eating disorders?

One of the issues raised by non-eating disorder specialists was that eating disorders is both specialised and complex in nature.<sup>59,61</sup> Eating disorders are considered 'rare, chronic and require intense care, high levels of treatment and high demand from HPs [health professionals]'.<sup>43</sup> Yet, it was regularly argued that eating disorder treatment should reflect its specialist need, and the best place for individuals with eating disorders is in specialist care<sup>43</sup> that provides the time and expertise<sup>43,61</sup> to build supportive relationships. Similarly, individuals with eating disorders and their family/friends perceived specialist eating disorder care as the 'best' or 'better' treatment for eating disorders,<sup>6,7,10,17,19,24,34,35,37,43</sup> providing better understanding and knowledge of eating disorders,<sup>2,3,9,20,25,43</sup> empathy,<sup>3,9,25</sup> and personal recognition.<sup>18</sup> Unsurprisingly, many non-specialist health professionals felt that they 'should' or 'would rather' refer individuals with eating disorders on to these services,<sup>43,55,57</sup> and many individuals with eating

disorders and their family/friends wanted this 'best' treatment too.<sup>6,7,10,17,19,24,34,35,37,43</sup>

However, 'referring on' often was to under-resourced specialist service struggling to respond to demand.<sup>19,25,35,43</sup> Eating disorder services created limited access,<sup>21,30,33</sup> geographical barriers,<sup>21</sup> long waiting lists and delays,<sup>1,19,21,30</sup> rigid admission rules based on single treatment modalities and eating disorder physical traits.<sup>21,25,30,33</sup> Lower body mass indexes took priority,<sup>26,30</sup> and referrals were only accepted for very serious cases.<sup>1,6,21,25,30</sup> Furthermore, specialist eating disorder care provided no guarantee of treatment even after gaining access,<sup>30</sup> with the risk of losing a place if another patient took priority<sup>25,30</sup> and immediate discharge occurring after weight restoration, with little if any aftercare.<sup>30</sup>

Eating disorders requires a multidisciplinary approach and team involved, including a range of primary and secondary care professionals,<sup>43,53,61</sup> with the inclusion of families.<sup>53</sup> However, this multidisciplinary model could suffer misconceptions, such as the assumption of professionals that 'some treatment is better than none'.<sup>43</sup>

Out-patient care<sup>10,11,35</sup> was favoured by some individuals with eating disorders as allowing a consultative and collaborative approach to treatment control,<sup>11</sup> and when delivered by a professional with sufficient eating disorder expertise, family/friends tended to feel that out-patient care is the most beneficial, compared with any other treatment.<sup>35</sup> To others, out-patient treatment was an unsuccessful, unsuitable or unskilled option.<sup>2,17</sup>

Medical general ward admissions were reported by all professionals, individuals with eating disorders and families as the most negative setting for eating disorders and the 'most inappropriate location', 'unsuitable and unhelpful' for individuals with eating disorders, making them feel isolated and treated by general ward staff who lacked skill and specialist eating disorder knowledge.<sup>1,2,4,7,17,34,40,43,48</sup> Professionals working on these medical general wards reported difficulties delivering care to individuals with eating disorders because of their 'deceitful and non-compliant' personalities<sup>48</sup> and reported a 'struggle to understand the complex disorder'<sup>59</sup> that challenged their nursing values, often causing more harm than good to the patients with eating disorders.<sup>48,59</sup>

Overall, specialist eating disorder care was considered the gold standard in eating disorder treatment. Unfortunately, this was not only often unobtainable, but emphasis as a 'best' care ultimately undermined other agencies, treating them as mere stepping stones to specialised services rather than potentially beneficial alternatives. It appeared to be the characteristics and techniques used – collaborative and patient-centred care that is knowledgeable yet sensitive to issues of control and ambivalence – that determined positive outcomes. Appendix 3 outlines the key points from theme 2.

### Theme 3: collaboration versus opposition

The third theme that emerged in the data is collaboration versus opposition in the treatment of eating disorders. This theme had two subthemes. Healthcare should be a partnership between the patient, families and the health professional.<sup>6,8,13,14,34,59</sup> However, in the case of eating disorders, a shared partnership in healthcare can often be lacking, with hostility and opposition, the misuse of power relations and a lack of collaborative care.<sup>2,6,7,9,11,13,59</sup>

The weight versus well-being paradigm

Perceived oppositions between the physical and emotional aspects of eating disorder treatment and recovery were identified. There is an opposition between the 'rarity' and 'recovery' aspects of eating disorders, as the prospect of recovery from eating disorders is often unknown, underestimated or overestimated among health professionals.<sup>44,49,53,56</sup> Anorexia nervosa was sometimes viewed as

chronic with no recovery prospects<sup>44,49,52,56</sup> whereas the prevalence and severity of bulimia nervosa was greatly underestimated.<sup>44,49,53</sup> In contrast, for individuals with eating disorders and their family/friends, the expectation of recovery drove help-seeking and treatment.<sup>1,14,16</sup>

Another opposition occurred between the professional and family members focusing on the 'visible signs of eating disorders' seeing physical status as the most valuable measure of treatment and recovery<sup>4,29</sup> as compared with individuals with eating disorders focusing on psychological markers such as improved 'well-being' and feeling 'normal'.<sup>1,8,18,20,23,29,30</sup> Overall, this lack of clarity resulted in a weight versus well-being paradigm and constituted a considerable barrier to the eating disorder healthcare interface frequently described by individuals with eating disorders and their family/friends as 'too much focus on food and weight',<sup>1,2,4,7,15,19,23,25,29,30,35,40</sup> reported in both primary and secondary care.<sup>30</sup> There is further conflation of completion of treatment with recovery,<sup>52,54</sup> with professionals measuring outcomes based on 'completion' of treatment, whereas individuals with eating disorders felt recovery should be based on 'doing well'.<sup>53</sup>

#### Power relations versus collaboration

Oppositions existing within the weight versus well-being paradigm were also reported as part of a 'power system'<sup>4,8,30</sup> throughout the eating disorder pathway, to the detriment of good practice.<sup>8</sup> Early in help-seeking and diagnosis, the overemphasis on 'weight and food' triggered a 'drive', because to 'eat less food and lose more weight' won individuals priority for treatment in specialist eating disorder services.<sup>30</sup> However, once entry was gained to eating disorder services, opposition between individuals with eating disorders and professionals continued, with healthcare professionals (for example secondary care staff in an in-patient unit) attempting to 'hold all the power'.<sup>4</sup> Some in-patient units used 'reward systems' based on penalties and privileges,<sup>8,15,33</sup> making individuals with eating disorders feel that professionals 'take all the power'.<sup>15</sup>

For some individuals with eating disorders, specialist eating disorder treatment was considered ineffective as this undermined engagement<sup>4,7</sup> leaving them disempowered<sup>4</sup> distressed<sup>1,17,18,25,29</sup> and patronised,<sup>7,33</sup> in a system that was too restrictive, structured and strict.<sup>18,21,23</sup> This resulted in loss of personal control, identity and normality.<sup>1,2,7,8,15,17,19</sup> Some individuals with eating disorders described these battles as triggering power systems, where rigid rules and unfair power relations forced individuals with eating disorders to become rebellious or deceitful, compelling them to 'put on an act'<sup>23</sup> as the 'perfect patient'<sup>8</sup> to comply, resulting in an opposing identity of the rebel.<sup>27</sup> This is reported as being detrimental to the health and recovery of the person with eating disorders<sup>23,27</sup> as it entrenched eating disorder symptoms and increased vulnerability.<sup>17,29</sup> For other individuals with eating disorders, restrictive treatment could be a 'safe haven'.<sup>18</sup> The loss of control and normality were considered positive<sup>1,9,15,17,18</sup> because it helped set boundaries and relinquish control,<sup>15,33</sup> relieving individuals of responsibility and allowing them to regain control 'elsewhere' as treatment progresses.<sup>18</sup> However, regaining control was problematic after discharge, especially if there was little aftercare.<sup>15,16,17,29</sup>

Professionals (for example secondary care staff in an in-patient unit) felt that too much authoritative control in the eating disorder treatment settings caused considerable stress for people with eating disorders and their families<sup>62</sup> and obstructed trusting relationships, causing rebellious outbursts among those with eating disorders.<sup>59</sup> For professionals, judiciously managing control was crucial,<sup>59,62</sup> without 'enforcing' it and triggering 'power in play' between the patient with eating disorders and professionals with resultant 'mutual mistrust'.<sup>48,59</sup> Family and friends of individuals with

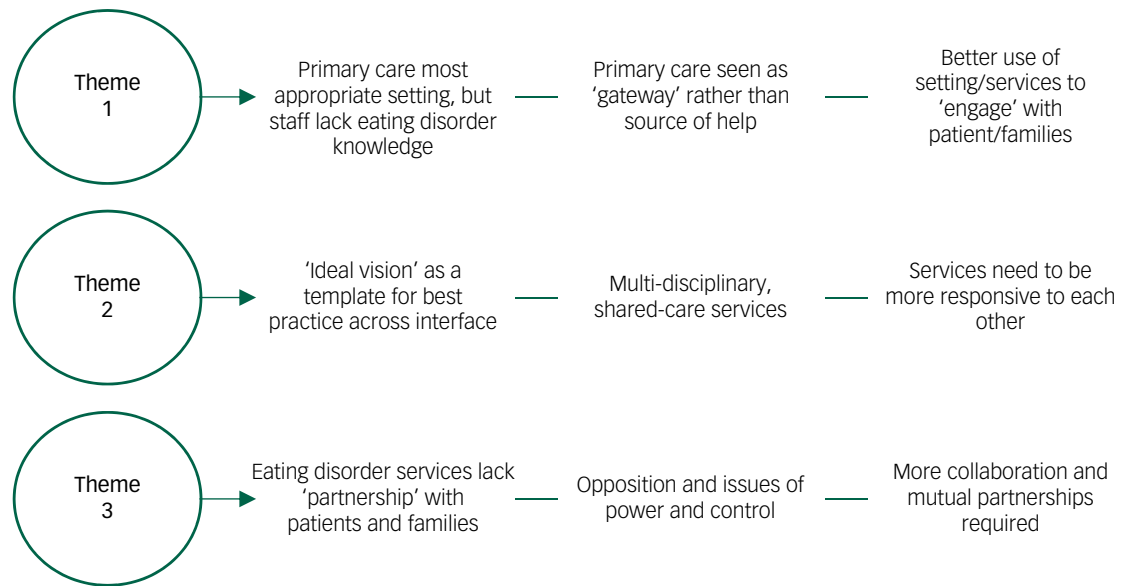


Fig. 2 Summary of themes.

eating disorders reflected that shifting their role in the home 'from power and authority to one of support and encouragement' improved outcomes.<sup>41</sup> Family and friends felt all sides should work together as a team<sup>36</sup> 'on the same page',<sup>41</sup> with all affected by eating disorders mutually involved in treatment and the recovery process.<sup>36,41</sup> Therefore, it was important to not remove all control and power from those affected by eating disorders<sup>11</sup> and professionals should adopt directional not authoritative stances<sup>9</sup> and be firm yet consistent.<sup>15</sup> In eating disorders, if power relations were distributed more fairly in the eating disorder care setting, the ultimate wish of all parties for more room for greater collaboration in eating disorder treatment would result.<sup>18,21,39,41</sup> Appendix 4 outlines the key points from theme 3.

Figure 2 outlines the key points in a diagram format of the three dominant themes and their additional subthemes

## Discussion

### Main findings

This review provides an overview of the facilitators and barriers existing at the current eating disorder healthcare interface from a range of perspectives and experiences. Overall, the initial blame and responsibility for existing barriers tends to fall on professionals in primary care. Many individuals with eating disorders and their families/friends view primary care as a gateway to access more specialised services, rather than seeing primary care professionals as sources of help for eating disorders. However, for primary care professionals this acts as a double-bind as they are variously held responsible by all parties for failing to be knowledgeable, treating insufficiently or referring on too readily or inappropriately, reducing their sense of professional competency. In summary, primary care professionals would benefit from more understanding of the needs of both individuals with eating disorders and their families/friends, and how to neither over- nor under-refer. The analysis suggests that rather than just being a gateway to specialist care, primary care professionals can and should play a crucial role in engaging ambivalent in individuals with eating disorders while supporting and advising families/friends in promoting recovery.

It may be important to challenge the gold-standard expectation attached to specialist eating disorder care, as its current status in the

eyes of individuals with eating disorders, their families and health professionals as the 'best' ultimately undermines all other services, dismissing primary care as a mere conduit, when it could potentially be a better alternative for some. This would require more training and support for primary care professionals to address their anxieties and difficulties in diagnosing, treating and supporting people with eating disorders. Specialist services need to be more responsive to primary care and improve shared care across the primary–secondary care interface for eating disorders. For example, as previously discussed in the background section of this paper, GPs in particular currently feel unequipped to identify and manage an eating disorder and prefer to pass the patient on to specialist services.<sup>8</sup> But, as this review suggests, if primary care were better supported by specialist services, they would feel more confident in their professional ability to work with patients with eating disorders.

The review suggests a complex function of the primary–secondary interface found in current eating disorder healthcare. This review adds to the knowledge-base and provides recommendations for moving forward in research and practice, these are in line with the generally accepted principles and values to deliver a better integrated service for all with shared partnerships and mutual responsibility.

The tensions identified in the final theme of collaboration versus opposition in the treatment of eating disorders are familiar. What is less familiar is the exploration of how this has an impact on the primary–secondary healthcare interface. The issues of power differentials and use of authority and control has ramifications when patients are discharged before they wish to be, or when medical responsibility is handed back to primary care. It is not clear in this review how the alterations in balance between collaboration and authoritative-ness or emphases on weight versus well-being are negotiated between specialist and primary care professionals, and this is an area for further research.

The geographic locations of the included papers were higher-income countries; it would be important to examine middle- or lower-income countries in future research. Furthermore, despite a 20-year publication range, there was consistency of themes across all papers, which suggests that little has been done in the past two decades to address these reported problems. Therefore, work is needed to address difficulties with the primary–secondary care interface for eating disorder services.



## Recommendations for an improved eating disorder service


Based on our research our recommendations are as follows.

- (a) More training and support for professionals is needed across the interface, especially in primary care settings to address the anxieties and difficulties in diagnosing and treating eating disorders.
- (b) Primary care professionals would benefit from more understanding of the needs of both individuals with eating disorders and family/friends, and how to neither over- nor under-refer.
- (c) While being a gateway to specialist care, primary care professionals need to better engage with and support individuals with eating disorders and their families/friends between waiting times and referrals.
- (d) It may be important to challenge the gold-standard 'best' expectation that is attached to specialist eating disorder care, as it may be undermining other services.
- (e) The 'ideal' vision of an eating disorder professional, setting and technique may be someone/something that can be used as a 'good practice' template.
- (f) It is important to link up services across the interface, adopting a multidisciplinary, shared-care approach.
- (g) This 'linked up' approach would require services across the interface to be more responsive to each other and upskill a range of professionals to fit the 'ideal' and 'best' care vision of services.
- (h) More collaborative understanding of eating disorders and mutual partnerships is needed across the primary–secondary interface to avoid the use of power and control, resulting in hostility and mistrust between partnerships.
- (i) More research is needed in this area to address the difficulties and challenges within the primary–secondary interface for eating disorder services.

## Strengths and limitations

This systematic review has identified many areas for improvement in clinical practice, and its findings can lead to concrete recommendations. The strengths of this study are the wide range of perspectives and experiences analysed from three groups of people, including people with eating disorders, families and health professionals across international healthcare systems. The limitations for this review are the lack of primary papers available focusing principally and/or specifically on the facilitators and gaps at the interface. As a result, these findings were gleaned from papers that had a main focus elsewhere. To ensure greater in-depth analysis of the data, a much larger set of primary data would be required.

In conclusion, this systematic review looks at a range of experiences and perspectives of the eating disorder primary and secondary care healthcare interface. Three dominant themes of 'the help-seeking process at primary care', 'expectations of care and appropriate referrals' and 'opposition and collaboration in treatment of and recovery from eating disorders' identify many facilitators and barriers existing at the interface. We suggest that attention to these issues could improve the quality of care and experiences of individuals with eating disorders and their families and the role of health professionals.

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## Supplementary material

Supplementary material is available online at <https://doi.org/10.1192/bjo.2019.48>.

## Appendix 1

### Study eligibility checklist

#### Inclusion

Studies employing both qualitative or quantitative methodology or mixed design primary studies.

Studies specifically focusing on eating disorders (anorexia nervosa, bulimia nervosa, binge eating disorder or eating disorders not otherwise specified).

Populations of:

- (a) people with eating disorders of all ages;
- (b) people close to/caring for people with eating disorders, such as family/friends;
- (c) primary/secondary health professionals.

Settings including:

- (a) primary (family physician/GP, nurse, community, general medical wards);
- (b) secondary (mental health, eating disorder specialist);
- (c) in-patient, out-patient, hospital wards, private, community, school/university etc.

Studies with a focus of perspectives or experiences of eating disorder healthcare.

No restrictions on date of publication or geographic location.

#### Exclusion

Non-English studies.

Secondary studies (for example reviews).

## Appendix 2

### Key point summary theme 1

#### Primary care

Individuals with eating disorders/families' view:

- (a) Primary care is the most appropriate setting to diagnose and provide initial interventions for eating disorders;
- (b) but a lack of eating disorder experience, understanding, knowledge and interest is reported in these settings;
- (c) these result in failure to detect eating disorders and provide timely diagnosis and referrals;
- (d) overall, primary care can inadvertently act as a barrier to specialist care, rather than gate-keepers

Health professionals' view:

- (a) Primary care professionals perceive their role as a 'double-bind':
  - (i) personal challenges with regard to skills in dealing with individuals with eating disorders and their family/friends,
  - (ii) clinical challenges and lack training or skills to diagnose and intervene,
  - (iii) organisational challenges, lacking resources, for example, difficulty in accessing specialist care;
- (b) need for a well-validated universal screening protocol for eating disorders in primary settings.

Utilising the primary setting:

- (a) currently, blame falls on primary care as it is considered a gateway to access more specialised services, rather than as sources of help;
- (b) primary care has the ability to play a crucial role in engaging individuals with eating disorders at the early-action stages of help-seeking, while supporting and advising families.

## Appendix 3

### Key point summary theme 2

#### Primary care versus secondary care

The ideal service for individuals with eating disorders and family/friends:

- (a) the ideal professional:
  - (i) has sufficient knowledge and experience of eating disorders,
  - (ii) is professional and confident,
  - (iii) is available and consistent and respectful, empathic and trustworthy,
  - (iv) is a person to build a therapeutic relationship with;
- (b) the ideal setting/technique:
  - (i) is somewhere that feels safe and supportive,
  - (ii) offers an individualised, yet collaborative approach to treatment,
  - (iii) is consultative yet directive with individuals with eating disorders and family/friends.

Specialist versus complexity of eating disorders:

- (a) eating disorders are both specialised and complex in nature, thus immediate referral to specialist care is generally considered the 'best' approach;
- (b) but over-referring can result in long waiting lists, delays and limited access;
- (c) this 'best' expectation of specialist care as superior undermines all other services;
- (d) a better system, which can be available to all, requires a multidisciplinary, shared-care approach;
- (e) this approach requires services across the interface to be more responsive to each other, and upskill a range of professionals to fit with the 'ideal' vision of services proposed by individuals with eating disorders and family/friends.

## Appendix 4

### Key point summary theme 3

#### The eating disorder healthcare interface

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

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