Workshop to engage with service users on eating disorders

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Background

Patient and carer involvement is an integral part of the SIGN guideline development process. To ensure patient and carer perspectives are reflected in the guideline on management of eating disorders, people with lived experience of eating disorders and people who have a support/caring role, were invited to take part in a workshop to discuss their views and experiences of accessing services.

This report summarises the feedback from participants attending the workshop and was presented to the guideline development group for consideration.

Participants and setting

The workshop took place on 27 August 2019. The Scottish Eating Disorders Interest Group (SEDIG) and Beat Scotland highlighted the opportunity to participate to their members in Scotland. People were recruited from Glasgow and Edinburgh.

Format of the workshop

The purpose of the workshop was to identify priorities for service users/carers when seeking support and accessing services, and to discuss what service users and carers value the most from treatment.

The themes from a patient-focused literature search highlighting patient and carer issues of concern were presented to the group using posters, allowing participants to consider, individually, the themes and 'what matters to them' in relation to each theme. Participants highlighted 'what matters to them' using post-it notes and stuck them on the relevant poster. Participants were asked to record their top 5 priority themes using coloured stickers. Discussions then took place around the themes.

Analysis of the post-it notes took place and a notes-based analysis of discussion from the workshop was carried out.

Results

21 people got in touch with SIGN's Patient Involvement Advisor and expressed an interest in participating. 10 people took part on the day, 8 service users, 1 parent and 2 people who have a role supporting people with eating disorders. Reasons for non-participation were 1) the date and time was not suitable 2) not feeling well enough to participate on the day. Equality monitoring of all participants highlighted that 50% of participants were aged 16–25, 90 % of participants were female.

Findings

The findings were grouped into themes defined by the patient-focused literature search.

A table summarising the findings can be found in appendix 1. The number of participants who rated themes as a priority is also shown. Quotations in relation to each theme are provided in appendix 2.

Comorbidities

Participants highlighted examples of comorbidities they had experienced, for example anxiety, and suggested the need for access to relevant services to ensure they were managed appropriately. The need for management of eating disorder and addictions was identified. Suicide risk and monitoring was an issue of concern for participants.

"It's [suicide] something that should be taken seriously and monitoring should be in place."

Ethnicity and other minorities

All participants were white but the need for healthcare professionals to adapt treatment to take into account the needs of people of ethnic origin was highlighted. Participants acknowledged that there is very little knowledge of eating disorders in some cultures. There was a suggestion that LGBTQ+ groups and men need to be considered by the guideline group.

Online communities

Some participants had used webinars and suggested that they were a good opportunity to host support chats. They acknowledged that online communities can be positive, for example Beat, but also that caution should be taken.

"There are so many negative spaces which can target vulnerable individuals. This is an increasing problem with new apps like KURBO."

Self help was identified as being important in treatment of eating disorders with a need for professionals to highlight to people where reliable self help should be accessed.

Exercise and athletes

Participants highlighted that the approach to exercise in children's services is very different to adults (told to rest completely vs encouraged to). They spoke about the need to give information and advice about returning to exercise.

Family and carers experiences

Participants discussed the need for more support for family and encouraging an understanding of eating disorders and how parents can best help. Inpatient care needs to involve parents/families so they are well informed and prepared to support their family member.

"Need to support parents so they can support their loved one, they can't do it if they don't know how."

Motherhood and pregnancy

Issues that were seen to be important to participants were the need for less focus on BMI etc while pregnant and the need for collaboration between services. The need for more information was also discussed.

Emotion/the self and personal meaning

Participants emphasised that there are issues that need to be managed other than just the eating disorder itself. Many felt that underlying issues were not addressed adequately and should be discussed.

Quality of life

Having quality of life was seen as a priority for participants. Some mentioned the need for support and financial help for medical and physical problems as a result of having an eating disorder. The impact of travelling to receive treatment on family life was acknowledged.

"We had to travel a long way to get treatment – travelling can take a long time and impacts on family social life."

Social support

The availability of social support including access to peer workers and support groups was highlighted as a priority for participants. The need for signposting to support organisations for people and their families was identified. The role of schools in offering social support to people with eating disorders was acknowledged.

"Recovery support groups are great. I found out about them through research. No professional knew about them."

Help seeking

Participants discussed their experiences of seeking help. They outlined a number of barriers including stigma, family not wishing to acknowledge eating disorders and waiting lists. Early intervention was identified as being essential. Participants felt there was a lack of knowledge from GPs on the referral process for people with eating disorders and the need for training for GPs and other professionals.

"Asking for help was hard and my GP didn't really know where to refer me."

Accessing treatments

Participants highlighted the need for early intervention and acknowledged how recovery is more difficult if treatment is delayed. Most people hadn't been offered a choice of treatment, with many receiving family-based treatment. Some participants benefited from family-based treatment and others felt they would have benefited from it but weren't offered this due to them bring treated by adult services. Others had negative experiences of family based therapy and cognitive behavioural therapy was seen to be of more value. Participants acknowledged the evidence for this treatment.

"I didn't get offered family-based treatment from adult services yet I was still living at home. Maybe that should be considered as it might help some people."

Participants felt they would have benefited from combinations of treatment, for example a combination of therapy and meal support. The benefits of schema therapy were acknowledged. The waiting time for accessing specialist services was discussed and participants highlighted the need for non-specialist counselling when waiting for treatment.

Participants felt there was a limited range of therapies offered when receiving inpatient care. Participants identified the need for collaboration between services when treating people with addictions.

The need for follow-up care once discharged from treatment and a suitable treatment plan were seen to be important.

Transition from child to adult services was discussed. Participants felt there was no support when moving from child to adult services and would have welcomed transition. They talked about the time delays they experienced before accessing services. Information provision on eating disorders for people and their families was acknowledged as an area for improvement.

Engagement in treatment

Participants discussed how care needs to be individualised and based on the wishes of the person. They felt strongly about the need for choice of treatment. Some had only been offered family-based therapy which they had found unhelpful. Others had positive experiences of family-based therapy but acknowledged that this may not be suitable for everyone.

The difficulty of seeing a different doctor each time was acknowledged and was seen as a barrier to engagement with treatment.

"Seeing a different doctor each time was difficult. Continuity of care and relationship with professionals is so important. People are seen as not engaging with services when they need time to build relationships."

Participants felt they hadn't been taken seriously and often issues they had raised were ignored. Barriers in inpatient care included not being able to work at their own pace. Participants highlighted how they had not felt involved or in control of their treatment and felt this was necessary.

Patient experiences and satisfaction of services

Participants highlighted difficulties accessing specialist help. They discussed how they were often seen as 'not ill enough' to get help due to strict guidelines based on weight.

"Getting passed around meant I felt like giving up - a clear pathway would help."

Recovery

Recovery was a priority area for participants. Using weight as a measurement for recovery was seen to be unhelpful – life achievements need to be considered. Support for adjusting to normal experience, for example eating out, is required for people. There was a preference for people to be involved in setting small goals for recovery. Participants discussed the lack of follow-up care once they were recovered. They felt there was a need for information about accessing services once discharged and signposting for help and support should they have a relapse.

"Once targets had been met, I was discharged without follow up. I quickly fell back into old habits."

Alternative treatments

Participants acknowledged that there aren't many alternative treatments that have evidence of benefit but they thought it would be useful to have the role of alternative treatments acknowledged.

"I would welcome any other treatments that can be recommended."

Conclusion

Providing individualised care and choice of treatments was seen as a priority for participants throughout their care. Gaining access to the right help and support for eating disorders and comorbidities at the right time would have resulted in greater satisfaction of treatment and services. Support when moving from paediatric services to adult services was regarded as essential in a

person's care.   Appropriate information provision throughout care for patients and their families was identified as an area for improvement.

People who expressed an interest in participating in the workshop but who could not attend due to the reasons mentioned, were invited to participate in consultation events.

Appendix 1

Theme	Findings
Comorbidities (priority n=3)	• Management of comorbidities associated with eating disorders needs improvement • Examples of comorbidities requiring treatment included obsessive compulsive disorder (OCD), post traumatic stress disorder (PTSD), complex post traumatic stress disorder (CPTSD), autism, diabetes and anxiety • Need for awareness/education that eating disorders impacts on other conditions • Treatment of comorbidities need to be addressed early
Ethnicity and other minorities	• Very little knowledge of eating disorders in some cultures • Need to consider how LGBTQ+ groups should be managed • Approaches for treating eating disorders in men needs to be considered
Online communities	• Webinars are a good opportunity to chat with others • Online communities can be positive • This is an increasing problem with new apps like KURBO
Exercise and athletes (priority n=1)	• Being able to exercise freely without feeling pressure – It is not becoming obsessive • Awareness and education needed for gyms – staff members and personal trainers, for example how to spot the signs of eating disorders and how to approach someone • Approach to exercise is different between child and adult services • Need for information on how to return to exercise
Family and carers experiences (priority n=2)	• More support for carers and family members needed • Need to encourage carers and family members to learn about eating disorders • Parents don't understand what's happening once child is in adult services • Not knowing where to turn for immediate support • Inpatient care needs to involve carers and family members
Motherhood and pregnancy	• Less focus on BMI while pregnant • More trained maternity staff with awareness that changing bodies can be a trigger • To be not seen as a set of numbers but as a person

Emotion, the self and personal meaning	• Underlying issues need to be addressed when treating eating disorder
Quality of life (priority n=7)	• Need for support and help for medical and physical problems as a result of eating disorders – infertility, bone health, dental health • Need to signpost for financial help • Need to involve people in their care and allow them to have a say
Social support (priority n=6)	• A more inclusive community of people who struggle with the same problem. Encourage open communication • Recovery support groups can be helpful • Social support offers help around social skills and managing treatment around school and social situations • Peer workers in services can help with social support • Peer workers of support groups can offer support to help maintain networks • Child and Adolescent Mental Health Services (CAMHS) offer support but people not aware of other sources of support
Help-seeking (priority n=4)	• Early intervention is a priority • Stigma acts as a barrier to people seeking help • Lack of knowledge of GPs on where to refer to • People being told they were not ill enough to receive help if not below a certain BMI
Accessing treatment (priority n=9)	• Being involved in discussions about treatment is essential • Consistent treatments and choice of treatment is important for recovery • Cognitive behavioural therapy (CBT) is positive and acceptable treatment • Family-based treatment can be positive for some and negative for others • No family-based support available once people move into adult services which some people can find damaging • There is a need to explore other issues, such as body image, perfectionism • Combinations of treatments were valued, such as CBT and meal support • Lack of therapy in inpatient units

	• There is a need for counselling when waiting for specialist treatment • Access to appropriate services for addictions is essential • Transition from child to adult services can be challenging • Need for information during transition
Engagement in treatment (priority n=2)	• Not been taking seriously is a reason for not engaging with treatment • Treatment from trainees rather than from professionals with experience can result in incorrect advice • Having to attend family therapy and open up in front of family can be a reason not to engage • Need for choice of treatment • Continuity of care and relationship with professionals is so important. Seeing a different professional each time was unhelpful • Care needs to be individualised
Patient experience and satisfaction with services (priority n=5)	• Need to involve patients in their care • Need for signposting to third sector organisations • Difficulty accessing services due to strict guidelines on weight • Choice of treatment would result in more satisfaction • Being aware of the pathway for referral and treatment would help
Recovery (priority n=8)	• Weight restored does not mean recovered – less focus on BMI • Recovery should focus on life achievements rather than weight alone • Follow-up care after discharge would be helpful • Information on what to do should there be a relapse
Alternative treatments	• Need to provide other treatments, not necessarily eating disorders specialist treatments

Appendix 2 Quotes from participants

Theme	Quotes
Comorbidities	
Ethnicity and other minorities	
Online communities	*"I have read articles online or googled to find out more information."* *"I used Beat online forum but I didn't find it helpful as it was only 2–3 people using it and it was only weekly. It was very slow as comments are moderated so this made it very difficult to use as a parent."*
Exercise and athletes	*"No help available to encourage me to exercise healthily. I was told not to do anything but I think structured exercise and social exercise would help. Form a healthy relationship with exercise again".* *"I would have appreciated advice on how to return to exercise again."*
Family and carers experiences	*"No provisions were ever made known to me regarding help my family could access to help them understand my condition."* *"Parents seemed to appreciate the group-based treatments we attended – gave them a chance to talk to others in same situation."* *"Family-based treatment was what made me recover first time round – no such support is given in adult treatment, parents don't really know what is happening."*

Motherhood and pregnancy	*"I witnessed an aunt go through IVF after not being able to conceive naturally due to her anorexia – triplets followed which has only just caused her to further relapse. It's so important that all other specialities are aware and people can be given support and access to the right services."*
Emotion, the self and personal meaning	*"Food is not really the issue. Issues might be control – maybe body image – these are the things that need explored."* *"There are usually other things 'egging on' eating disorders, eg perfectionism. If you don't tick boxes you don't get treated."*
Quality of life	*"You can live a great life eating disorder free. You can be happy and successful."* *"Involving people in treatment means they will get the care they want and need to lead a good life."*
Social support	*"When I moved to uni, I didn't know who to go to for support. I didn't know if I could get more support because I was discharged. Needs to be a follow up."* *"Speaking to recovered people can help but some people might not know how to access them and healthcare professionals don't highlight this opportunity."* *"We could cook meals together."* *"A man's experience is different to that of a woman. There is less support around for men."* *"There has been no social support for me as a parent and it takes over your life. I have managed to keep working. You carry a lot of guilt and blame."*
Help seeking	*"GPs need to look for signs of bullying and abuse in children. This is often overlooked."* *"I first spoke to my guidance counsellor and she didn't deem it an issue as I was still functioning academically. I now realise had she signposted me, I could have got help much earlier."*
Accessing treatments	*"I was not taken seriously until my weight was so low."* *"Treatment options were not given to me. The route to treatment was hard and full of protocol barriers that made me want to give up asking for help. It shouldn't be difficult to get help for eating disorders."*

	"Family-based therapy can make encouraging independence difficult in the longer term – needs to be a balance to allow for transition to adulthood." *"I could choose when to talk when I felt ready. Family therapy puts pressure on"* *"The need for different levels of treatment at different times was highlighted. Residential (recovery) focused intense therapy, therapeutic community and intensive home treatment"* *"I would have welcomed a proper transition when I moved from child services to adult services. I didn't know what to expect. No-one told me what was going on and I had to figure it out which added to the pressure."* *"Accessing appropriate services for people who haveeating disorders and addictions is essential"* *"Too often people are discharged with no follow up, I would really have benefited from a follow-up appointment not so long after I was discharged to make sure I was coping."* *"Often discharged from specialist services once perceived to be a healthy weight but treatment still needed"* *"Information about eating disorders, would have been helpful. I had to look it up myself and then you don't know it the information is right."* *"I'm not really sure that I was aware that there was a plan for treatment. I think it was trial and error. It would be useful to share any treatment plans with people."* *"I didn't want my little sister involved, I didn't want her to hear things. The team listened so it's important to ask people what they want."* *"I went to see what an inpatient unit was like. It helped me to stay focused and encouraged me to attend outpatients as I didn't want to be an inpatient."*

	"Early intervention is essential. I was a healthy weight and it dipped in a month. At that point I needed treatment."
	"There is a need for counselling when waiting for specialist help, would make it less daunting and you would feel like something is happening."
	"I was anxious about food, how do you deal with food anxiety at social events around food?"
Engagement in treatment	*"It was difficult to open up when my family were there so I sometimes didn't turn up."*
	"My daughter was resistant to being hospitalised. As parents we agreed with this – it was a disconnect."
	"Treatment seems to be done to you rather than with you."
	"Taking control away from the person is sometimes helpful and sometimes damaging to relationships."
Recovery	*"Setting small goals needs to come from the person."*
	"Often the hardest part is coming to terms with life without being underweight and reintroduction to normal life."
	"Recovery support groups are great. I found out about them through research. No professional knew about them."
Alternative treatments	*"Would be good to have role of alternative treatments acknowledged."*
	"Not all about weight and eating."