Telephone helplines as a source of support for eating disorders: Service user, carer, and health professional perspectives

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Abstract

Access to care for eating disorders can be problematic for numerous reasons including lack of understanding and delays with treatment referrals. Previous research has highlighted the benefits of telephone helplines as an accessible source of support for those who may not wish to access face-to-face support or to fill a gap for those waiting for treatment. This study aimed to gain an insight into the perspectives of those who may use or refer others to a telephone helpline in order to identify the requirements of such a service. Triangulation of service user, carer and health professionals' perspectives resulted in identification of themes relating to the type of support, delivery and practicalities of a helpline. The findings indicated that telephone helplines may offer numerous benefits for individuals with an eating disorder, whether accessed as a first step, alongside treatment or as an extension of this support when in recovery. Additionally helplines may provide an opportunity for carers to access information and discuss their own experiences, while supporting their loved one. Raising awareness of these services is important to encourage those affected by an eating disorder to access and make the most of this type of support. These findings offer an insight into the key requirements for new and existing service development with regard to both the type of support and the method of communication required by individuals with eating disorders

Word Count
5899

Introduction

Treatment services for eating disorders are often difficult to access, with services provided by the National Health Service (NHS) in the UK often being limited (Button & Warren, 2001; Escobar-Koch *et al*, 2010; Reid *et al*, 2008). Barriers to accessing these services include long waiting lists; lack of knowledge held by General Practitioners (who are considered the 'gatekeepers' to treatment); and difficulty accessing services if considered 'normal' weight (Escobar-Koch *et al*, 2010; Koskina *et al*, 2012; Leavey *et al*, 2011; Reid *et al*, 2008). In particular students who change general practitioner when living away from home may experience disruption in the continuity of their treatment (Treasure *et al*, 2005). Contact with GPs has been highlighted as problematic due to a lack of understanding and empathy (Button & Warren, 2001; de la Rie *et al*, 2006), delay in treatment referral (de la Rie *et al*, 2006) and services not meeting clients' needs (Leavey *et al*, 2011). Recently a survey conducted by Beat, a UK charity providing support for people with eating disorders, suggested that many sufferers may be trapped in a six year cycle of treatment, recovery and relapse (Beat, 2015). Findings indicated that almost half of sufferers did not seek help until a year or more after recognising symptoms. Individuals were then found to have experienced considerable delays in obtaining a diagnosis and accessing treatment, with 18% waiting two years or more for treatment (Beat, 2015). These findings highlight the need for not only improved access to treatment services but also the increased availability of alternative support services.

Aside from accessing treatment services individuals have reported concern with the lack of continuous care following eating disorder treatment, particularly in an inpatient setting, where individuals may reach their target weight and yet still have on-going psychological issues (Escobar-Koch *et al*, 2010). Improved transition from treatment back into everyday life and support following discharge may help to prevent the risk of relapse (Escobar-Koch *et al*, 2010; McCormack, 2010). As individuals with AN are known to be difficult to engage in treatment (Goldner *et al*, 1997; Joyce, 2007; Treasure & Schmidt, 2001) it has been suggested that they may find a telephone helpline service beneficial (Rees-Davies *et al*, 2011). Individuals with eating disorders have diverse and complex needs (Reid *et al*, 2010) and in particular individuals with AN are thought to have differing needs with regard specifically to telephone helpline support (Latzer & Gilat, 2005). Speaking directly to individuals who are currently experiencing or have experienced AN will therefore provide an insight into their specific requirements. Furthermore taking a co-production approach and

involving users within service development ensures individuals feel their voices are heard (Long et al, 2010).

Accessing treatment services may be frustrating for carers (Highet *et al*, 2005) and there is a need to investigate the views of non-professional carers (Swain-Campbell, 2001). Carers of people with AN often have a large number of unmet needs and may want practical support with coping strategies and the opportunity to speak to others in similar situations (Haigh & Treasure, 2003). Supporting someone experiencing the physiological and psychological effects of an eating disorder can be heart-breaking and lead to feelings of helplessness (Highet *et al*, 2005), guilt and self-blame (Honey & Halse, 2005). Understanding the complexity of AN as an illness and knowing how best to help the person can be difficult for carers even when trying to educate themselves (Whitney *et al*, 2005).

In order to be effective, a tailored telephone helpline service addressing the specific concerns of the population to help bridge the gap between health professionals and those who may access the service is needed (Turner *et al*, 2000). Previous studies into telephone helplines for health conditions more generally have considered the views of the service users calling the helpline (Plummer & Allan, 2011) and the call handlers delivering the service (O'Shea, 2006). However, research into the views of helplines from health professionals' involved in the care of individuals with AN or any other eating disorder is lacking. Health professionals may provide additional information regarding the complex requirements of individuals with AN and highlight practical aspects that may need to be considered.

In order to make recommendations for new and existing services it is important to consider the views of those who may use a telephone helpline. Previous research has noted the value of using a triangulation methodology to investigate the features of a high quality eating disorder service, gathering information from the perspectives of sufferers, carers and professionals (Nishizono-Maher *et al*, 2011). Building on this triangulation model, the present study explored specifically how telephone helplines may provide a source of support to individuals with AN from the perspectives of these three groups. Data were collected in two stages; 1) interviews and focus groups with service users, carers and health professionals and 2) a questionnaire distributed to service-users throughout Wales, UK.

**Study One: Exploratory Interviews and Focus Groups**
Method

Participants

Four service users, four carers and five health professionals were recruited via Clinical Psychologists working within an NHS eating disorder service. Participants were recruited based on the following inclusion criteria; 1) Service users currently receiving or who have received treatment within Wales within the last year (diagnosis made by clinician in the Welsh Healthcare system); or 2) Carers involved in the care of people with AN; or 3) Health Professionals involved in the care of people with AN.

Design

A mix of interviews and focus groups were used to overcome challenges relating to conducting qualitative research on sensitive topics (Dickson-Swift et al, 2007) and meet the requirements of participants. Two individual interviews were conducted with service users (SU) while one service user was interviewed with their parents upon request. Two further individual interviews were conducted with carers (C). One focus group and an individual interview were conducted with health professionals (HP) and were arranged in this way to fit in with work schedules. A follow-up focus group then brought together two service users, one carer and one health professional, all of whom had previously been interviewed (see Figure 1).

Figure 1: Groupings for interviews and focus groups
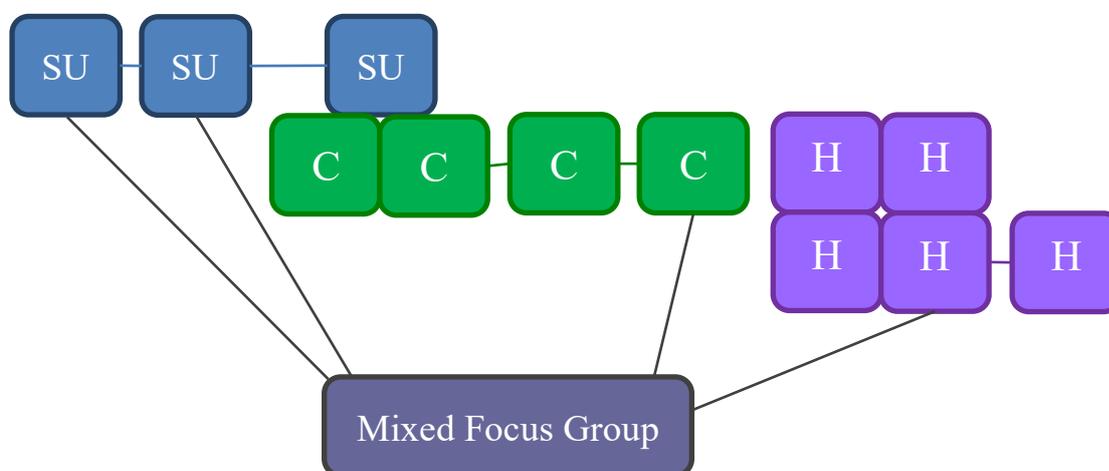
Development of Interview and Focus Group Schedule

The interview schedule covered eight topics; general views of helplines, helpline provision, management of calls, caller expectations, availability and relevance of helpline, satisfaction with service, type of caller, other services for eating disorders. As this was an exploratory study, questions were relevant to all three groups of participants. The schedule for the follow up focus group was developed following analysis of the initial interviews and focus group with the three groups. The follow up focus group was included to allow participants involved in the previous stage of the research to come together and clarify key issues identified.

Ethical Considerations

Ethical approval was obtained from the NHS Research Ethics Committee, the Research and Development Unit for the Local Health Board and the Cardiff Metropolitan Health Sciences Ethics Committee. When contacting participants to take part in the mixed follow-up focus group, care was taken to ensure that services users had not received treatment from the health professionals involved. Service users were provided with the names of the health professionals in order to determine this. Health professionals were not provided with service user information.

Data Analysis

An inductive thematic analysis (Braun & Clark, 2006) was used to analyse the data and identify key themes for further discussion in the follow up focus group. Reliability was checked using a three phase approach involving consideration of two external researchers' views. The second stage of analysis involved a deductive approach to analyse the follow up focus group data and clarify findings from the initial interviews and focus group.

Figure 2: Thematic Map outlining the key themes and subthemes relating to a telephone helpline for eating disorders.
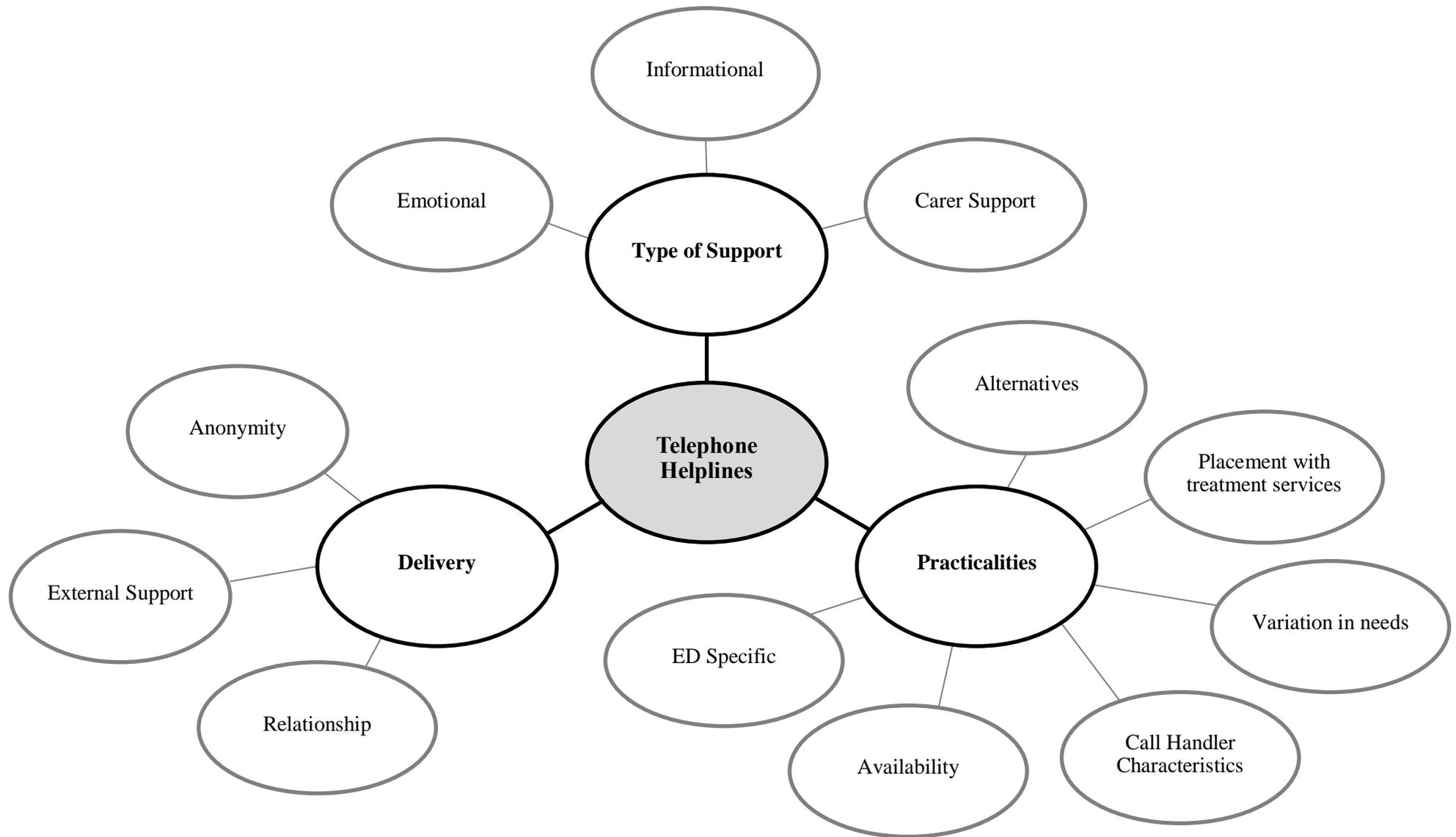
Study One: Exploratory Interviews and Focus Groups

Results

Interviews and focus groups lasted between 30-70 minutes each. Three main themes were identified following thematic analysis of the interviews and focus groups with service users (SU), carers (C) and health professionals (HP); 1) type of support, 2) delivery of support; 3) practicalities of service delivery (figure 2).

Theme One: Type of Support

'Emotional support' was a valued aspect of helplines, offering the opportunity to talk through difficult issues to someone understanding and willing to listen especially during times when individuals may feel isolated and unable to express their thoughts and emotions to anyone else.

> *"somebody to talk to who understood some of the challenges of trying to recover from an eating disorder" (HP5, p3, L74-75).*

Talking may help individuals to distract themselves from engaging in unhelpful behaviours and in some cases provide encouragement with treatment.

> *"if you've eaten you get these awful feelings of guilt and you, it really cuts you up and you feel you know like you want to purge ... you could you know pick up the phone and talk your feelings through rather than actually go and do something about it" (SU3, p1, L4-7).*

'Informational support' incorporates the provision of specific information, guidance and signposting to individuals. For example guidance relating to approaching health professionals and accessing treatment was viewed to be important.

> *"general advice for the patient, where to go and get help ... there's not a lot of advice readily available" (C3, p2, L65-69).*

While provision of this guidance is valuable, it was noted that this would not be enough to replace treatment and therefore it is important to manage the expectations of service users.

"it would be difficult to provide anything that was more in depth and I think what would be useful would be to have a helpline that had a very clear remit that people have very clear expectations of what they could have when they did ring up" (HP5, p2, L63-65).

'Support for carers' was perceived to be currently lacking and participants felt that those in a caring role may feel isolated. Participants suggested a helpline would enable carers to access information and advice from someone with an understanding of the illness.

"it can be quite hard to understand from an outside point of view and … know how to react to somebody who's got anorexia so I think yeah it would be really useful to get advice on how to deal with it and how to help them best" (SU4, p10, L319-322).

Theme Two: Delivery of Support

'Anonymity' when contacting a telephone helpline may encourage callers to be open and honest while feeling safe and more comfortable when discussing sensitive issues. Participants felt that the possibility of being identified may prevent some people from using the service.

"it's sometimes easier to say things over the phone when you're not face to face and you don't have to worry about what do they think of me" (SU1, p2, L57-59).

However it was also noted that while anonymity was viewed to be positive, there may be an issue with lack of face to face contact and therefore conversations would lack the additional non-verbal cues present in body language.

'Caller - call handler relationship' and the development of trust with service providers was felt to be an important part of accessing support via a helpline. Continuity was also discussed and the importance of being able to speak to a familiar voice and avoid individuals having to keep repeating their story.

"it's annoying to have to explain over and over and over I feel like I want a bar code so people can just scan me" (SU2, p6, L200-201).

However issues relating to dependency and service provider availability that could make providing continuity problematic were noted.

> "*so that would be the only danger if somebody expected a one on one service with a particular person and they didn't get it then that may cause problems*" (C1, p11, L356-357)

'External source of support' related to the participants' view that individuals may wish to speak to someone who is not involved in their everyday life. This may be helpful where individuals feel unable to talk to family members and friends.

> "*people in your everyday life … you can tell them quite a lot but you wouldn't necessarily want to tell them unnecessary details and cause them distress or let them know about any active behaviours that you're not ready to stop*" (SU2, p9, L310-313).

Theme Three: Practicalities of Service Delivery
'Eating Disorder Specific' support as opposed to general mental health support was preferred. Service providers were expected to have a broad knowledge of eating disorders and an awareness and understanding of the specific issues that may arise during this illness.

> "*there would be big benefits from providing something that's specific to people with eating disorders because I think that there are issues that are particular to eating disorders … especially around the confusion and uncertainty that people experience around recovery*" (HP5, p3-4, L95-98).

Additionally it was felt that service providers should be aware of co-morbid illnesses to ensure the appropriate support or signposting is provided.

> "*things are all interlinked it's not like you've got anorexia … you've probably got anorexia, depression, impulses, OCD … all those can cause more distress than the eating disorder*" (SU2, p9, L292-294).

'Availability' of support may be particularly valuable for individuals who have been waiting a long time to receive treatment or need someone to speak to between appointments.

> *"to know that you've got some sort of support ... cos when you need it you need it then and now not in three weeks" (SU3, p9, L293-294).*

Participants expressed a clear preference for 24 hour support but also noted the practical difficulties with providing this level of support.

> *"I would say 24 hours but I don't think that's very feasible really is it ... you can't always guarantee what time somebody's gonna need to talk to someone. It's quite difficult to man a 24 hour helpline" (C3, p5, L146-149).*

'Call handler characteristics' including level of experience, knowledge and professional manner were all thought to have an impact on the experience of using a helpline. Participants highlighted that an excellent understanding of eating disorders and related issues, whether from personal or professional experience is essential.

> *"quite calm and not over react or be shocked at anything, it's most important to ... not think or say 'oh my god' ... that makes them feel worried and more anxious and nervous" (SU4, p5, L153-155).*

Participants indicated that while it is important for individuals to be trained in a way that ensures they deliver support appropriately, they do not necessarily need to have any specific qualifications.

> *"as long as risk issues are dealt with and people have a general sense of support and being non-judgemental ... it doesn't feel like it needs to be a doctor ... just somebody who is supportive" (HP4, p5, L156-160).*

'Variations in caller needs' were noted as participants highlighted that helplines can provide support during the early stages of an eating disorder and again during recovery as well as to fill in gaps during treatment.

"for people who are contemplating engaging with services, dipping a toe in and just getting a flavour of what it's like to talk to somebody about making the change" (HP3, p7, L228-230).

"recovery is the hardest part, the support that's really missing at the moment is … when everything stops at the end. Cos everything stops and then if you don't do the transition right it's just being abandoned again" (SU2, p13, L443-445).

'Placement with treatment services' refers to the links between a telephone helpline and treatment services. Carers felt that if individuals were receiving treatment then the health professionals delivering this should be made aware that they were also using a telephone helpline for support.

"as long as the service knew that … my sister was using a helpline on the phone too, I don't think it should be kept as a secret that no-one knows that she's using it" (C3, p7, L213-215)

While health professionals agreed that it would be beneficial for treatment services to offer telephone support for continuity, this appears to be a different service compared to an independent helpline. Inclusion of a helpline within an existing treatment service would presumably only offer support to current patients and therefore individuals who are not yet in treatment or who are in recovery would not be able to access this. It was also felt that access to a separate support service may provide individuals with a sense of power if they feel they can choose to access this support on their own terms.

"I think there is also an element that so much power is taken away from the client … something that they choose to do themselves could be empowering" (HP2, p3, L79-82)

'Alternative methods' of communication such as online live chat, email and text support may be accessed by those who find it difficult to talk on the phone and wish to use a more discreet service. Online discussions may prompt individuals to seek support via phone once they feel more comfortable.

"an instant messaging thing so you get feedback straight away and then ... if you're starting to trust the service then be able to ring up, I dunno I think I'd find that easier" (SU4, p2, L48-50).

Study Two: Questionnaire

Method

Design

Key themes identified in study one informed the development a questionnaire involving both qualitative and quantitative components.

Participants

Service users were given the opportunity to participate in the questionnaire study if they had a current diagnosis of AN or had been discharged within the past year. All service users who met these criteria were contacted unless the lead of the ED service felt it would be inappropriate to contact them based on their health at the time. Postal questionnaires were distributed to 135 service users throughout Wales via the ED service within each health board. 40 responses were received indicating a 30% response rate.

Development of Questionnaire

Nine questions relating to the themes identified from the interviews and focus groups were included in the questionnaire. One question related to the theme 'Type of Support' as it asked participants to provide information on all types of support that should be provided. Two questions related to the theme 'Delivery of Service' as they asked about the caller-call handler relationship and about the level of anonymity a helpline service should have. Five questions related to the theme 'Practical Aspects' and asked about characteristics of the call handlers, availability and specificity of the service and how a helpline should link with existing services. Participants were required to select their answer from the categories provided; by ticking one or all relevant categories (depending on the question). Nominal categories were used, for example when asked about availability of service, four options were provided '24 hours', 'day only', 'night only' and 'other'. Five questions provided an 'other' option with space for participants to write an alternative response. Four questions asked participants to explain their answer by providing a qualitative response. Validity checks involving discussion of both the content and presentation with health professionals involved in the care of individuals with eating disorders and experts in the field of Psychology, ensured that the questionnaire was appropriate prior to distribution.

Analysis of Data

Following data collection, qualitative sections of the questionnaire were analysed using deductive thematic analysis based on the themes previously identified from the focus groups and interviews (Braun & Clark, 2006). Descriptive statistics from the quantitative questions were collated.

Study Two: Questionnaire

Results

Views of Telephone Helpline Services

Type of support

Emotional (87.5%) and practical support (90%) were the main types of help that individuals felt a helpline should offer. Information (72.5%) and signposting to relevant services (70%) were also identified as important. Additionally support for those indirectly affected by eating disorders was highlighted with 82.5% of participants indicating that they felt a helpline should provide support for family members/friends.

Delivery of Service

Overall 75% of participants reported a preference for remaining anonymous or choosing whether to provide their details. Qualitative responses indicated that individuals may wish to provide their details in order to receive additional support information.

> *"Many will feel safer and less threatened if they are able to remain anonymous*
> *… others may wish to receive further support by post … many may feel that*
> *trusting the helpline worker with their name etc. is an important part of*
> *establishing a therapeutic relationship…" (Q31)*

Developing a relationship appeared to be important with 52% of participants expressing a preference to speak to the same call handler each time they called and 20% reported that they would like the choice to speak to the same person.

> *"The choice of handler would depend on the problem. Emotional*
> *problem/support would probably prefer to speak to a handler that I've connected*
> *with previously. For information wouldn't mind who the handler was" (Q39)*

Practical Aspects

Support specifically tailored for eating disorders was preferred by the majority (62.5%) of participants compared to only 7.5% who said they would prefer general mental health support.

"There are plenty of non-specific phone lines for all sorts of issues but to have a place solely dedicated to it instils more faith that you won't be ridiculed" (Q11)

Provision of support for 24 hours a day, seven days a week is needed according to 87.5% of participants, however qualitative responses recognised the potential limitations with this.

"Ideally 24 hour but practically would be best 12-midnight" (Q1)

With regard to staff running the service, responses indicated a preference for either personal or work experience relating to EDs or those working as health professionals. This indicates the need for individuals to have a clear understanding of the complex nature of eating disorders and associated issues in order to support callers effectively.

Many participants (47.5%) expressed a preference for a helpline with links to existing eating disorder services where helpline staff may be aware of the treatment already received in order to provide continuity and familiarity for individuals.

"It might be useful to talk to call handlers who know you, are aware of the treatment that you are receiving" (Q39)

Some participants (22.5%) felt that a separate service would be beneficial. The option of speaking to someone regarding issues occurring within treatment and times of crisis were noted, as well as accessibility for individuals not receiving treatment.

"Provides independent advice and available to those not in treatment" (Q37)

Use of Telephone Helpline Services

Although 30% participants reported having used a telephone helpline service, most participants reported that they had not used a helpline (70%). Participants were required to answer a set of questions relevant to whether they had or had not used a helpline before, findings for each response will be presented accordingly.

Results for participants who reported using a helpline (12 participants):

Almost all participants reported that they had used a helpline that was specifically for eating disorders (91.7%) and the majority of participants reported using a helpline on a one-off occasion (58.3%). Participants reported calling a helpline for emotional support (83.3%), practical support (41.7%) and information (41.7%). Responses showed overlaps between these categories indicating that individuals called a helpline for more than one reason. When asked about use of alternative support services, five people (41.7%) reported using an online forum; four people (33.3%) had used email support and three people (25%) had used an online chat room.

The questionnaire responses from those who had used a helpline indicated mixed levels of satisfaction; six people (50%) reported being either very or somewhat satisfied;

> *"The particular helpline service I contacted was very good and offered follow up telephone counselling, which was helpful" (Q1)*

However, five participants (41.7%) reported being somewhat or very dissatisfied with the helplines they had used and one person reported a neutral view. Reasons for dissatisfaction related to the availability of services, lack of knowledge and understanding held by call handlers and the feeling of being 'let down' by the helplines used;

> *"Having rung [general helpline] I was left to educate the responder about anorexia, when all I wanted was someone to help/understand. [Helpline staff] were rather judgemental – all responses felt pre-written/patronising" (Q11)*

When asked about which areas would need to be improved the majority of participants felt that helpline availability was an issue (91.7%); with other aspects also being highlighted as areas for improvement; call handler responses (58.3%); type of support (58.3%); information provision (58.3%) and delivery of service (25%).

Results for participants who had not used a helpline (28 participants):

The reasons for not accessing telephone helplines are outlined in Table 1. Qualitative responses for 'other reasons' suggested that this may in some cases be due to participants already receiving treatment or the belief that they are beyond help;

"Although I didn't know about a helpline I probably wouldn't have used or use it in the future as I'd seek help from professionals involved already" (Q12)

"I would guess it wouldn't help me, the problem is too big" (Q18)

Table 1: Reasons for not Accessing Telephone Helplines

	Participant Responses	
Reasons for non-use	**N**	**%**
Did not know about them	16	57.1
Prefer face to face interaction	11	39.3
Do not like talking on the phone	7	25
Do not need helpline support	6	21.4
Prefer online support	2	7.1
Other	10	35.7

When asked if they had used any support services instead they reported using an online forum (17.9%) and email support (17.9%). Some said they used instant online live chat (10.7%) or chat rooms (7.1%) and two people (7.1%) reported receiving support via a letter. Other support services accessed were mentioned by three participants (10.7%) and qualitative responses indicated these were inpatient services and eating disorder support websites.

When asked if they would consider using a telephone helpline for support in the future, 14 people (50%) agreed that they would, ten people (35.7%) said they would not use a helpline and four people (14.3%) chose not to respond.

Overall Summary of Findings

The interview and questionnaire findings identified the requirements of telephone helplines and the current utilisation of these types of services. In order to ensure the support provided meets the needs of those who may choose to access them, current and future services should consider the following key qualities (Table 2).

Table 2: Key Requirements identified by service-users, carers and health professionals

Who should support be for?
Additional source of support for individuals with eating disorders in times of need; as a first step to seeking treatment, to fill the gap when waiting for treatment to begin and in between appointments and/or to provide continuity during/following recovery.
Support for carers who may need to discuss challenges they face while supporting a loved one with an eating disorder.
What type of support should be provided?
Emotional support with on-going issues: encouragement, listening ear, help with issues relating to seeking and completing treatment.
Informational support: information and signposting to relevant local services.
Provision of support specific to individuals with eating disorders.
How should this support be provided?
While practicalities may prevent this support from being delivered round the clock, it is envisaged that this would be available outside of the usual working hours to extend the support offered to individuals with eating disorders.
Anonymous support allowing service users to speak freely about their ED.
Opportunity to develop a trusting relationship with those delivering the service while maintaining appropriate boundaries for safety.
While staff members delivering support via a helpline do not have to be health professionals specifically, they should receive robust training. Staff should hold an excellent understanding of eating disorders to ensure service users feel listened to, understood and taken seriously.
Source of support outside individuals usual social support network and provision of an alternative perspective to those of family members and friends.
Alternative methods of communication available alongside helpline are beneficial and ensure the differing needs of service users can be met.

Discussion

Triangulation of service user, carer and health professionals' views have provided a valuable insight into the preferences relating to telephone helpline support. Questionnaire responses provided further support for the preferences of service users and started to explore how well used telephone helplines are and why.

Emotional and informational support for both sufferers and carers was an important expectation of a helpline; individuals expressed the need to call the service to offload and discuss challenges with someone who understands. Talking was thought to reduce isolation, provide encouragement and offer distraction from unhelpful behaviours. This is supportive of previous literature highlighting the importance of providing a friendly voice (Mental Health Foundation, 2012) and the opportunity to talk (Roy et al, 2006), while feeling listened to and respected (Fenner & Kleve, 2014). Information and signposting to support services and treatment was discussed, for example; thinking through what to say when approaching the GP may help the individual to feel prepared and get their point across clearly to ensure the GP has a clear understanding of their needs and therefore provides appropriate support (Button & Warren, 2001; de la Rie *et al*, 2006). Provision of information and opportunity to discuss this with a call handler in times of need (Ingram et al, 2008) may encourage individuals to access treatment services (Latzer & Gilat, 2000). Access to support via a telephone helpline may offer the opportunity for individuals to talk through any psychological issues they may be dealing with once their official treatment has finished. Findings from Federici & Kaplan (2008) indicated that individuals felt their recovery process was on-going and yet their follow up care after receiving inpatient treatment lacked social support. A telephone helpline may provide a sense of continuity for individuals so they do not feel lost after finishing treatment. Provision of this support while transitioning back into everyday life may help to reduce the risk of relapse (Escobar-Koch *et al*, 2010; McCormack, 2010).

One of the key benefits of a telephone helpline service identified by participants was the anonymous aspect and the knowledge that the conversation would not be shared with anyone else. Service users said they would feel more comfortable discussing sensitive issues over the phone, which supports research indicating that anonymity may lead to a more open discussion (Boselli et al, 2003) and be helpful to those who find face to face support difficult (Mental Health Foundation, 2012). Knowing that information discussed with a call handler will remain confidential also links to the importance of trust and an anonymous service

therefore would enable callers to feel safe and regain a sense of control (Reese et al, 2006). While participants expressed a preference for an anonymous service, they also expressed a preference to have the option to speak to the same call handler so they can develop a rapport. In order to overcome this disparity, it may be that completely anonymous support may be helpful when callers have a question or want a brief chat, however if on-going support is required and individuals are happy to provide their details or even just a pseudonym, then speaking to a familiar person would avoid problems of repetition and create continuity (de la Rie *et al*, 2006). Further investigation of this from the perspective of staff delivering support via telephone helpline would help to clarify the most appropriate option here. Speaking to someone who is not involved in the individual's daily life was highlighted as another positive aspect of a telephone helpline. It may be that family and friends have too much of an emotional investment in the individual with the eating disorder and therefore it is easier for the sufferer to talk to someone neutral without fear of being judged or causing upset. For individuals receiving treatment, speaking truthfully about their treatment goals and progress may be topics that callers would prefer to discuss anonymously with someone neutral who can present a different perspective (Mental Health Foundation, 2012).

Delivery of an eating disorder specific service was preferred to ensure that those manning the helpline have excellent knowledge and understanding of eating disorders and are able to respond to callers appropriately. There is a need for robust training to be put in place to support call handlers in their role. Training may involve the provision of specialist knowledge about eating disorders (Gulliksen, 2012) to ensure call handlers know how to communicate with callers effectively. It was suggested that this training should be guided by health professionals who have an in depth understanding and experience of working with eating disorders. Knowledge through training would further increase call handlers' understanding of callers' situations and ensure the support offered meets the callers' needs (Reid et al, 2008). It seems that individuals with eating disorders experience barriers when trying to access treatment such as a lack of understanding and empathy (Button & Warren, 2001; de la Rie et al, 2006) and therefore telephone helplines need to avoid falling into the same trap and failing to meet people's needs (Leavey et al, 2011). Appropriate training therefore will help call handlers to build positive and trusting relationships with callers (Horvath et al, 2011). Awareness of varying needs is essential to ensure individuals are supported whether it is the first time they have sought support for their eating disorder or they are in the process of recovery. While signposting to treatment services is important it was felt overall that a

telephone helpline should provide an independent source of support to empower individuals to take control of their own recovery as well as to allow access out-of-hours and to those not receiving treatment (Pinfold, 2003). Finally, online forums and live chat were also highlighted by participants as being a beneficial source of support that may be preferred by some individuals who wish to retain a higher level of anonymity. This is in keeping with previous research that outlined benefits including anonymity, accessibility and a useful way of taking the first step to treatment (Buchanan & Coulson, 2007; McCormack, 2010). Participants in the current study suggested that online support and texting can offer a discreet first step to seeking support via telephone which may gradually build up to face to face communication. Online video calls in comparison may provide an opportunity to speak face to face and therefore still involve the non-verbal cues that get missed during phone conversations. While the findings from this study provide some much needed insight into the requirements of helplines as highlighted by Ingram et al (2008), further investigation from the service providers' perspective is required. Many existing support services available in the UK offer telephone helpline and online support and therefore it is important to investigate how these services are run in order to determine whether they are meeting the varying needs of individuals with eating disorders as discussed in this paper.

This study has highlighted the key qualities of telephone helplines that may be of interest to new and existing services. These key qualities aim to provide a compromise between the perspectives of services users, carers and health professionals in order to balance the preferences and practicalities associated with delivering a helpline service. Continuing to raise awareness of the availability of these services is required as lack of awareness was one of the main reasons for non-use of helplines. Other reasons reflected the requirements discussed during the interviews, including the importance of knowledgeable and understanding call handlers. Despite numerous benefits being discussed, most participants who completed the questionnaire had not used a helpline. While these findings should be considered with caution due to the sample size, they indicate the need to investigate the use of helplines and related services in further depth. Inclusion of individuals with a diagnosis of AN was important in order to identify the specific needs of this group, however use of these services for other eating disorders including those without a confirmed diagnosis of an eating disorder should be investigated. The findings from this study did not indicate that service users felt a helpline should be available specifically for individuals with AN. Instead they confirmed that helpline staff should have an in-depth understanding of the complex nature of

eating disorders and knowledge of the variations and overlaps between the different diagnoses in order to support individuals effectively.

In conclusion, this study has highlighted the preferred requirements of a telephone helpline based on a triangulation of service user, carer and health professionals' views. Further evaluation of the utilisation of telephone helplines and sources offering online support would be beneficial to provide an insight into how these services are currently being delivered and made use of by the public. Furthermore consideration of how they could be improved to ensure they are helping to fill the gaps in current service provision and provide valuable support for people with eating disorders and their carers. With continuing cuts being made to services within the healthcare sector it is important to investigate and develop methods of supporting those in need in a timely and cost effective manner. Development of services delivered via telephone and online outlets can offer an extension to those delivered face to face and provide support in an accessible way for individuals to seek support and manage their recovery.

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