

# **Chapter 10. Using Qualitative and Mixed Methods Approaches to Investigate Online Communication about Eating Disorders: A Reflective Account**

Dawn Branley-Bell

Department of Psychology, Northumbria University

## **Introduction**

Online communication around eating disorders (EDs) represents a common source of public concern, and the focus of many media headlines (e.g., “TikTok: Fears videos may ‘trigger eating disorders’, Lantos, 2020; “Instagram eating disorder content ‘out of control’”, Crawford, 2019; “Social media is fuelling eating disorders among children as young as twelve”, Chalmers, 2019). There are two major concerns often expressed within the media; Firstly, the possible reinforcement of ED behaviours through normalisation of the behaviour, i.e., making the user feel that this behaviour is acceptable, justified and in extreme cases perhaps even desirable (Bine, 2013; Schroeder, 2010). Secondly, the potential for ED-related material to ‘trigger’ ED behaviour in vulnerable users (Branley & Covey, 2017; Eikey & Booth, 2017). These concerns have been heightened due to social media use being heaviest amongst younger users, who also represent the age group most heavily affected by EDs (Arcelus et al., 2011). However, it is crucial to recognise that online platforms can play a positive or a negative role, depending upon the context and the user(s) involved. For example, online communication has been linked to improved mental health wellness (Asbury & Hall, 2013), increased social connectedness (Highton-Williamson et al., 2015; Naslund et al., 2016; Smith-Merry et al., 2019), increased coping (Smith-Merry et al., 2019), emotional

support (Wright et al., 2003) and empowerment (Barak, 2007). Social media can also provide a platform through which users can find support and guidance on treatment and recovery (Branley & Covey, 2017; Branley-Bell & Talbot, 2020b)—this is particularly important as individuals experiencing EDs rarely seek professional help (Ali et al., 2020; Hart et al., 2011). Further research is needed to fully understand online communication around EDs and to identify protective interventions to enable us to protect against negative impacts whilst avoiding disruption of positive communication networks; as the implementation of a poorly guided intervention could unintentionally disadvantage the majority of individuals.

This chapter is a reflective account of my own research experience within this field, reflecting on the use of qualitative and mixed methods approaches. I will describe some of the techniques I have applied whilst striving to capture an accurate portrayal of online communication around EDs. Applied responsibly, I believe that qualitative, and mixed methods techniques can help to highlight the valuable voice of lived experience. Throughout this chapter I reflect upon the design and ethical challenges I have encountered and aim to share some of the lessons that I have learned along the way.

## Background

Before diving into the methodological considerations, I want to first take some time to explain why research in this domain is important, and why we must strive, as researchers, to provide an accurate insight and portrayal of online communication.

Online communication about EDs is not a new phenomenon. Long before the introduction of social media, internet users have been using technology to share, discuss and access ED-related content. Although the arrival of Web 2.0 brought with it the introduction of social media platforms, prior to this, traditional websites and online forums were used for these discussions (Branley, 2015; Lipczynska, 2007). That said, as social media has become so

mainstream within our society, it has helped to move online communication about EDs into the public eye. This has fuelled public concerns around negative impacts; this section begins by discussing the driving factors behind these concerns, and how they are linked to stigmatising public discourse. The discussion then turns to positive elements of online ED-related communication and highlights why greater awareness is needed to provide a more complete view of the ‘bigger picture’.

### **Stigmatising public discourse & fears about online communication**

The nature of EDs—particularly the behaviours associated with these disorders and the high mortality rate, alongside concerns for the well-being of our loved ones—can predispose us to focus on the negative aspects of online communication. The mass media helps to fuel public concerns with headlines drawing attention to the possibility of social contagion effects or extreme online content such as pro-ED websites. However, the media has been described as focusing on “an oversimplified picture of pro-ED platforms viewed only in terms of ED maintainers” (Smahelova et al., 2020, p. 634). Just because the internet provides a communication channel for users, does not necessarily mean that it plays a role in the development or persistence of EDs. It is for this very reason that my early ED research focused on capturing a more complete picture of online ED communication, seeking to extend beyond the narrow pro-ana focus depicted in the media.

Early research in this field tended to focus upon extreme content (e.g., Brotsky & Giles, 2007; Lipczynska, 2007; Norris et al., 2006; Tong et al., 2013; Yeshua-Katz, 2015). Before I continue, I wish to be clear that I am not disputing the existence of extreme online content, on the contrary there are aspects of online communication that are concerning. One example is the sharing of extreme ‘thinspiration’ or ‘bonespiration’ images (Branley & Covey, 2017; Talbot et al., 2017). I completely agree that damaging or harmful content should be

addressed. However, as I found in some of my earlier research, this type of communication is likely to represent the minority rather than the 'norm' (Branley & Covey, 2017).

Furthermore, recent research suggests that it may not be as simple as categorising material into either pro-ED or pro-recovery content, as user motivation may be a much bigger factor in influencing the impact that online content has upon the viewer. To quote Smahelova et al. (2020):

“Even platforms centered on nonprofessional recovery, platforms providing professional help, and platforms providing regular information about food, diet, and exercise can be used for maintaining the illness. On the other hand, in the recovery phase, nonprofessional pro-ED platforms could serve as a challenge and a “waking up point” for some participants, and that could enhance the recovery process. As a result, the usage of each kind of online platform is intertwined with the motivation of the participants rather than the type of the platform and the purpose” (p. 634).

This suggests that to categorise online content as explicitly negative or positive may be too simplistic - the bigger picture is likely to be much more complex! I believe that research is needed to help increase our understanding and raise public awareness that society needs to move away from an oversimplified, alarmist approach. We need to understand more about users' motivations and other contributing factors related to positive or negative outcomes of online communication.

### *Raising awareness of positive aspects*

In seeking to illustrate the deeper complexity of online communication about EDs (and indeed online communication about mental health more generally), researchers need to raise awareness around positive aspects. This could feed into a more balanced societal view.

Benefits of online communication are not unique to EDs; research continues to highlight positives across many domains, for example online communication can help to alleviate loneliness (Leavitt et al., 2019), provide a source of support for physical and mental health (Pretorius et al., 2019; Zhang et al., 2017), and help to raise awareness and address stigma (Chen & Yang, 2016). Back in 2014, as part of my doctoral research, I conducted an investigation of online communication about EDs on social media (Branley, 2015; Branley & Covey, 2017). Using ED-related search terms, I used the live firehose to capture 12,000 tweets and 73,000 Tumblr blogs, over a 24-hour period. I applied inductive, thematic analysis to identify indicators of user motivation(s) for sharing ED content. My results showed that pro-ana content was in the minority and that the majority of users appeared to be communicating about EDs for positive reasons; including sharing and inspiring recovery, challenging pro-ana views, raising awareness around EDs and challenging social norms. Since then, many researchers have continued to demonstrate the positive aspects of communicating about EDs online (e.g., Kendal et al., 2017; McLean et al., 2019; McNamara & Parsons, 2016).

More recently, a colleague and I researched the impact of the COVID-19 pandemic on the lives of individuals with experience of EDs (Branley-Bell & Talbot, 2020b). Our findings show how technology and online communication can play a positive role for this population, particularly during stressful and socially isolated periods such as the pandemic 'lockdown'.

Since the start of my research career, I feel that there has been a gradual shift of opinion within the research community, with increasing awareness that online communication around EDs is not necessarily negative and that a more comprehensive view is necessary.

Thankfully, professional bodies are also beginning to recognise the positives of online

communication, with ED charities such as Beat ([www.beateatingdisorders.org.uk](http://www.beateatingdisorders.org.uk)) recognising the importance of positive online spaces and even embracing these platforms by offering their own support through Twitter and Instagram. However, there is still much work to be done in relation to addressing public opinion and that often depicted in mainstream media.

### *Implications of public and media perceptions*

I have already touched on the clear disconnect between perceptions of online communication within the research community and that within the media and society. On one side, there is negative media coverage, stigmatising societal norms, and fears around online communication. Whilst on the other there are researchers and individuals with lived experience who are recognising that online communication can also be driven by positive motivations and/or lead to positive outcomes. But you may be wondering why this disconnect in opinion is so important. Well, negative public perceptions can be linked to significant, negative implications. For example, individuals experiencing EDs traditionally report experiencing feelings of being misunderstood, misrepresented and stigmatised (Ali et al., 2020), and they commonly experience loneliness and social isolation. Media and public misconceptions around online communication can worsen this, subsequently negatively impacting upon the wellbeing of this population. Furthermore, negative perceptions of online communication could lead to calls for censorship. However, research (including my own, e.g., Branley, 2015) suggests that such censorship could impact upon positive sources of support, access to recovery information and other aspects of recovery and coping facilitated by online platforms.

The internet has the potential to provide even more benefits, for example by increasing accessibility to healthcare treatment using remote delivery (Branley-Bell & Talbot, 2020b;

Talbot & Branley-Bell, 2020). Thus, broadly labelling all ED-related online communication as negative could “create barriers in the treatment process because internet usage can also offer positives” (Smahelova et al., 2020). From my own research experiences, I strongly believe that focusing too heavily on the negative, can result in us missing the ‘bigger picture’ and the positive opportunities that online communication affords us.

My experiences and perceived advantages of qualitative ED research

Qualitative methods have a lot to offer ED research to help address the issues discussed in the previous section. Based upon my own experiences, reflections and lessons learned, I would like to discuss three key benefits of qualitative approaches: *i. Staying true to the voice of lived experience, ii. Understanding and adopting a shared language, and iii. Creating generalisable insights in a rapidly evolving online environment.*

#### *Staying true to the voice of lived experience*

In my opinion, one of the main benefits of qualitative research is the ability to *stay true to the voice of lived experience*. It is vital that we gain insight into the lived experience of individuals who communicate about EDs online. I certainly do not wish to imply that quantitative approaches do not have merit, far from it! Quantitative research can provide us with valuable insights into trends and relationships, and enable us to test the significance of predictive factors linked to recovery or relapse. Indeed, in my own research I often apply a mixed-methods approach to allow the empirical testing of quantitative methods (including longitudinal studies which can track change over time) to be complimented with the rich insight of qualitative methods.

When wishing to capture and explore the voices of lived experience, qualitative approaches really come into their own. They provide us with the best tools to seek deeper understanding

of the factors and thought processes underlying behaviours. Qualitative data can help explain how individuals make sense of their own world, their perceptions, and thoughts. I have personally found qualitative approaches invaluable in allowing me to create a dialogue with the individuals taking part in my research. For example, open-ended questions allow participants more control over the direction of the conversation and they may raise a point that I had not initially considered, but which turns out to be a valuable contribution to the research. I also find that there is immense value in being able to probe and prompt further discussion to gain clarification and/or to check my own interpretations of the individual's account. The latter can be particularly useful when paraphrasing quotes as this provides an opportunity to double check that I have interpreted the participants words in the way that they were intended (I will return to the issue of paraphrasing later in this chapter).

### *Understanding and adopting a shared language*

I have also found qualitative approaches to be invaluable in helping me to *understand and adopt a shared language* with my participants and/or target audience. Qualitative methods provide insight into the language used by individuals with lived experience. I have often found it surprising just how often the terminology used in public reports or research could be perceived as shaming or inappropriate. For example, in some of my recent collaborative work, I have been investigating the 'Better Health' campaign (Talbot & Branley-Bell, 2020). Launched by the UK Government as a response to the COVID-19 pandemic, this campaign was designed to "encourage millions to lose weight and cut COVID-19 risk" (Public Health England, 2020). The campaign was influenced by data showing that obese people are significantly more likely to become seriously ill with coronavirus compared with non-obese individuals (Docherty et al., 2020; Hussain et al., 2020). However, when it was first launched the campaign used wording such as "war on obesity" and "protect the NHS, save lives"



which were branded stigmatising and shaming by ED charities and specialists (Mead, 2020). Interested in the public reaction, my colleague and I analysed Tweets referencing the campaign. Our findings suggest that the use of inappropriate language may have reduced the campaigns effectiveness, and may have been harmful to vulnerable populations (Talbot & Branley-Bell, 2020). Shaming language is particularly worrying as individuals with EDs traditionally report experiencing negative stigma and show low levels of professional help-seeking (Ali et al., 2020; Hart et al., 2011). Furthermore, during the COVID-19 pandemic (and shortly before the introduction of the Better Health campaign), individuals with EDs were already experiencing feelings of shame and perceptions that they were burdening the ‘overwhelmed’ NHS if they were to seek help for their ED (Branley-Bell & Talbot, 2020b). Campaigns using inappropriate and/or shaming language have the potential to decrease the likelihood of individuals seeking critical healthcare. We reflected upon the campaign placing a strong emphasis on weight loss (rather than health more generally) and its potential to trigger vulnerable populations (Talbot & Branley-Bell, 2020). This is just one example of how a disharmony in language can represent a considerable barrier between individuals experiencing EDs and those aiming to promote positive change. When conducting research, it is vital to have a shared language (Yorke et al., 2020) and qualitative approaches can help us to establish this.

### *Creating generalisable insights in a rapidly evolving online environment*

*“But you need to have a backup plan, in case the internet is just a phase!”*

You may think the above quote sounds absurd now, but back when I was proposing ideas for my doctoral research, this is exactly the type of response I received. Many academics were concerned that I was ‘hedging my bets’ on a technology that may simply be a passing phase. I was asked to consider what my backup plan would be if the internet fell out of favour and

was no longer used by the masses. Of course, this quote is one of the extreme examples. Digging deeper, it became apparent that most of the apprehension was more accurately described as a concern over *social media* being just a phase. Again, this may seem unlikely now, as social media has become firmly ingrained in our everyday lives, but it was not such a stretch of the imagination back then!

Reflecting on the previous 1-2 decades, it seems likely that social media will be around—in some shape or form—for a long time to come. However, there is still merit in discussing how to prolong the longevity and relevance of your research. As a Cyberpsychologist, I am very aware of the incredibly rapid pace in which this research environment evolves! Platforms come and go (remember Google+ and Myspace?) and we must account for this in our research. No researcher wants to dedicate a significant chunk of their research career to a study that is resigned to the history books in an incredibly short space of time! Of course, our research is not always going to be ‘cutting edge’ but we can at least use the methods we have to help prolong its relevance. Qualitative insight can benefit us in this regard. For example, deeper insight into the underlying factors and user motivations behind behaviour, can make it easier for us to identify if research conducted on one (perhaps since obsolete) platform may remain relevant to other platforms. Including more than one social media platform can also be beneficial; I use this approach to help me identify if there are overarching themes evident across the platforms (of course, if they are not—that also makes for interesting discussions, for example considering what aspects of the platform environment may explain these differences).

#### Methodological considerations

Having explained why I believe qualitative approaches represent an important tool for research in this domain, I would like to use the following section to highlight my experiences

and reflections in relation to some specific design challenges and considerations: *i. Avoiding pre-conceptions and the importance of co-design; ii. Ensuring confidentiality and privacy; iii. Promoting openness; iv. Considering language and terminology; and v. Representing the bigger picture.*

#### ***Avoiding pre-conceptions and the importance of co-design***

It is important for me to be critical in my research and to take the time to consider whether I am bring any pre-existing bias or preconceptions. Although this is important for any research, I am particularly aware of this issue when working in a field that is so often sensationalised in the mass media, and one prone to societal stereotypes and stigma. Individually, both 'internet usage' and EDs can be highly emotive, controversial subjects, and this is amplified further when investigating the interaction between the two!

It is important to recognise that we are all influenced by the world around us. As responsible researchers, we need to stay alert to potential influences and choose methods which help us to capture the true lived experience of our participants. We must design our research with the aim of obtaining an accurate reflection of the target population's behaviour, motivations, experiences, attitudes, and beliefs. For this reason, I generally use inductive approaches to allow themes to be generated from the data (also referred to as a bottom-up approach), rather than approaching the data with pre-determined hypotheses or themes which may lead to increased chances of misinterpretation.

In my own experience, I have found co-design to be a valuable tool to reduce potential bias or misinterpretation. Co-design (also sometimes referred to as experience-based design, participatory design or coproduction) involves end-users in the entire research process. For example, within a health context, co-design can involve patients, carers and staff (Boyd et al., 2012). I have found that this approach can really help shape and strengthen my research

designs, methods and interpretations; partly by helping to identify limitations and possible sources of bias. Using co-design to work alongside individuals with lived experience has been not only incredibly rewarding, but also essential for increasing the scientific integrity of my research.

There is another significant benefit of this approach, namely the opportunity for individuals with lived experience to be more actively involved with research (i.e., rather than limiting them to the role of ‘participant’). I strongly believe that research, and interventions, should be designed alongside those with lived experience—rather than something that is imposed upon them by researchers, healthcare professionals or governmental bodies. Co-design affords those living with EDs the opportunity to help share their valuable insight to influence the body of knowledge, interventions, health care services and/or policy. Thankfully, the benefits of this approach are being increasingly recognised and co-design is being more widely adopted and encouraged (Talbot & Branley-Bell, 2020).

### *Ensuring confidentiality and privacy*

*“But is it really public, or is it private-public?”*

This quote represents a dialogue I find myself revisiting when planning research which uses online data. Online platforms provide an interesting, and somewhat unique, ethical dilemma when it comes to privacy. Whilst in offline situations it may be relatively clear cut, the distinction between what can be considered public or private often becomes blurred when talking about online environments. This becomes an issue when capturing online data that exists in the ‘public’ domain (e.g., social media data) where it is not always possible to obtain informed consent from the original user. Traditionally, the British Psychological Society (2014) ethical guidelines suggest that use of data in the public domain is acceptable in

situations where users can reasonably be ‘expected to be observed by strangers’ (p. 25).

However, this can be somewhat of a ‘grey area’ when it comes to online platforms.

Interestingly, this dilemma goes above and beyond whether the information is actually publicly accessible, as online spaces and platforms can also differ in their ‘*perceived public*’. Privacy online has previously been described as “less about public vs. private [i.e., privacy settings] and more about whether you are findable and identifiable by people who actually know you in real life” (Rifkin, 2013, para. 8). In my earlier research, I described a distinction between perceptions of ‘*private-public*’ and ‘*open-public*’ spaces (Branley, 2015, pp. 104–105). For example, Twitter users are generally very aware that this is an openly public domain, used by the mainstream population, and that their tweets are likely to be seen more widely. However, other platforms may be regarded as more private spaces, where it is unlikely that others besides the intended audience are likely to frequent - even though *technically* there are no privacy settings preventing public observation. There are many factors which could underpin the perception of a *private-public* including platforms which are regarded as less mainstream, harder to find, or those that offer more anonymity (Branley, 2015, pp. 104–105). Therefore, considering what is public from an ethical viewpoint—in the online environment—can require careful consideration. In my own experience, it can often be useful to discuss this with others who have experience in the field.

Even if data is deemed appropriate for collection and analysis, it is vital that steps are taken to ensure privacy, confidentiality, and anonymity of the users. One issue I feel strongly about, is ensuring anonymity when using social media data. As students we may have been generally taught to remove names and identifiable information from data to ensure anonymity.

However, this is not adequate within the online domain:

Removing their username ≠ anonymity!

Due to the ability to easily and quickly search online, it is very important to avoid directly quoting online content. Even more so when the research concerns sensitive subjects! Directly quoting what someone has said online means that the user could quickly be identified by running a web search for that text. Of course, if the data was obtained with informed consent from the participant to publish their quotes, this is not an issue. However, participant consent is often not possible or feasible—and in this instance, I have relied upon two approaches in my own research: Firstly, if it will not detract from the strength of the research, I tend to avoid the use of quotes in my papers and instead focus upon writing about the general themes and findings. However, sometimes the inclusion of quotes is particularly valuable for strengthening the research and/or improving reader comprehension. In this instance, I have used paraphrasing (e.g., Branley, 2015, p. 117; Talbot & Branley-Bell, 2020). Paraphrasing refers to rewriting the same information in a different way, by making word, sentence and/or grammar changes. The aim is to rewrite the idea(s) expressed by the original author but retain the original meaning. One lesson I have learned is that paraphrasing is not as easy as it may initially seem! Considerable care must be taken to accidentally avoid altering the meaning of the text. Paraphrasing is something I regard as a multiple person task; aim to have at least two researchers independently paraphrasing the text, and only include quotes once there is consensus between the researchers that the original meaning of the message has been retained (e.g., Branley, 2015, p. 117; Talbot & Branley-Bell, 2020).

Watch out for that hashtag!

Another lesson I have learned along the way, is to pay particular attention to the use of unique terms—even if using otherwise paraphrased text. One particularly unique or unusual term could result in the user being easily identifiable with a quick web search. The same applies to user-generated hashtags. Searching for a unique hashtag (e.g.,

#ICantBelieveIBurnedMyToast) as opposed to a mainstream, widely adopted hashtag (e.g., #Weekend) can immediately bring up the corresponding social media post—even if the rest of the quote is completely paraphrased. Once I've paraphrased a quote, I often run a quick web search to check that the original result is not easily found.

It can be tricky to know which steps to take to ensure privacy and confidentiality when conducting online data collection. For example, it is important to carefully consider the security of online platforms used to conduct interviews and/or store data. This can involve checking the platforms terms and conditions to identify if data is accessible by any third parties and using platforms with secure data encryption wherever possible. As I previously mentioned, the online environment evolves rapidly, and with it so do the ethical considerations involved. Luckily, there are useful resources available to help inform online research, which are regularly reviewed and updated. For example, in my own line of research I often refer to the British Psychological Society (BPS) 'Ethics Guidelines for Internet-Mediated Research', which is accessible via the guidance section of their website ([www.bps.org.uk/article-types/guidelines](http://www.bps.org.uk/article-types/guidelines)). All researchers have a responsibility to keep up to date with recent developments and updates to ethical guidance, at least within their own field.

### *Promoting openness and selecting appropriate platforms*

Although online research methods can be tricky, they also provide many advantages and opportunities, particularly for research involving potentially sensitive subjects such as EDs. Technology provides us with many different platforms and methods for data collection, and I have found this hugely beneficial for increasing participant ease and promoting open discussion. I take time to consider the types of methods that are both suitable for my research aim(s), and also likely to be well accepted by the individuals I would like to take part. Where possible, I have found that offering a range of participation methods/platforms is beneficial as

individuals differ in their preferred type of interaction. For example, many people can feel uncomfortable taking part in telephone or face-to-face interviews—particularly if they are discussing a topic that they find difficult or uncomfortable to talk about. Of course, there are others who prefer audio and/or visual interaction and video or audio calls can be valuable in this respect.

I have found that some participants prefer using online text-based messaging platforms. Reasons include eliminating the need for face-to-face interaction, increased anonymity, and less pressure for an instantaneous response (for example, compared to the awkwardness of silent moments during a face-to-face interview or audio/video call). This can decrease participation anxiety and promote open and honest discussions (Branley, 2015).

From a practical perspective, with text-based platforms the data is effectively already transcribed! This can save a considerable amount of time and expense. On the other hand, there are certain language cues (such as pauses in conversation, and emphasis on words) which can be lost when using a text-based platform. As with all methodologies, it is about weighing up the pros and cons and making a balanced decision which considers your specific research design, aims, and participants.

### *Considering language and terminology*

I have already touched upon the importance of using appropriate language. In reality, I have found that this can be very daunting as a researcher, as you may worry about accidentally using less-than-ideal terminology. Being aware of the impact that language can have, can make you acutely aware of the risk of accidentally wording something incorrectly. I find that the best way to address this, is not only to understand the existing academic literature but also to speak to healthcare professionals in the field and crucially, with the target population—i.e., individuals with lived experience. The latter are best placed to provide insight into terms that



they personally find shaming, judgemental and/or inaccurate. Reassuringly, I have found that people generally appreciate that I have taken the time to ask their opinion and check their preferred terminology.

### ***Representing the bigger picture (including to the media and public)***

Earlier I mentioned how I have tried to avoid focusing on extreme online communication in my research and aimed to capture the bigger picture. Within this section, I would like to share some of the methods I have used to achieve this.

When planning one of my earlier studies, I realised that existing research tended to collect data by using search terms specific to pro-ana (e.g., Brotsky & Giles, 2007; Lipczynska, 2007; Norris et al., 2006). I realised if I was aiming to capture ED communication more generally, this had to start with my chosen search terms. I broadened the terms from pro-ana specific (e.g., #proana, #pro-ED) to include more generic eating disorder terms (e.g., #eatingdisorder, #edproblems). To help identify other appropriate terms, I used a hashtag search tool (such as hashtagify.me) to identify other words commonly associated with the term 'eating disorders'. Reflecting upon this, I am particularly grateful that I broadened my search terminology. Without doing so, I would have only captured the extreme minority of my sample. The results would have been very negative, as the data collection would only have captured content designed/shared to *promote* disordered eating behaviours. By widening my search terms, I discovered that most users in my sample were actually using the internet for more positive reasons. In fact, most of the messages in my data set were dedicated to what I later termed pro-recovery (i.e., content designed to encourage recovery in the user and/or others) or *anti* pro-ana (i.e., content specifically challenging the pro-ana mentality). In sharing this experience, I hope that this helps to demonstrate how research findings and

conclusions can be significantly impacted by the decisions we make in the early stages of our research, and how bias can be so easily, and unintentionally, introduced.

Of course, research into the negatives and/or extremes of online communication is also very important. This can lead to greater understanding, earlier intervention for vulnerable groups, and improved support mechanisms. However, I feel that we should also strive to encourage balanced research designs that can help feed into a more complete societal view of online ED-related communication. Unfortunately, working within this field I have discovered that even with the best research design, researchers may still find it difficult to ensure accurate mass media coverage of their research. All too often I hear from fellow researchers about their research being misquoted in the media with an overly sensationalist headline (usually one that is negative and alarming). This can be particularly distressing to the researcher who can find their valuable 'take-home message' and research implications overshadowed by the attention-seeking headline. I empathise with researchers feeling apprehensive about media coverage of their research, due to concerns of misrepresentation. Thankfully, my personal experiences of the media thus far have generally been positive. However, I have picked up a few quick tips that may be helpful for some readers:

Focus on the 'take home message'

Personally, prior to a media interview, I find it helpful to identify the key 'take home message(s)' that I would like the media to portray, and I focus upon getting that across in a clear, concise manner. Framing my research this way also helps prevent me from attempting to cover too many aspects of my research during the interview and in doing so, losing the emphasis on the key message. It is important to remember that media quotes and footage will be cut down significantly during editing - and the more you talk about during the interview, the more likely it is that your take home message will be one of the bits that's cut!

Talk to the reporter—they're human too!

When I receive an interview request, I find it very helpful to talk to the journalist/reporter to establish which angle they are approaching the report from. This is something I now do regularly, but prior to any interview experience, I remember being unsure whether this was an accepted thing to do! Reporters tend to be happy to discuss the best way to approach the topic, and this can really help you get a feel for the potential direction and tone of the interview. In some instances, it is also possible to request interview questions ahead of an interview, or to review the quotes or recorded footage prior to the story going live. It certainly doesn't harm to ask!

Another aspect that is easy to overlook, is the imagery used by the press or other dissemination outlets when presenting your research. It can be helpful to discuss what images will be used, as an inappropriate image could portray your work in a negative or inaccurate light. For instance, it is generally advisable to avoid imagery that portrays or strengthens an ED stereotype, neutral imagery is often more suitable. Of course, imagery may not always be within the researchers control but it does pay to ask about these things whenever possible.

Don't forget to get your research 'out there'!

I also believe that it is hugely important that researchers strive to engage with the public and other non-academic audiences to help promote increased understanding around EDs and online communication. This can help to increase awareness of positive findings which may not always receive the media publicity of the more extreme and/or negative findings. To help achieve this I try to disseminate my research to policy makers and governmental bodies, for example to help improve public messages and health campaigns (e.g., Talbot & Branley-Bell, 2020). I also look for opportunities to take part in public events, to help disseminate my research findings to a non-academic audience and/or provide public reports that can be

disseminated through non-academic channels such as through ED charities, public websites and blog posts (Branley-Bell & Talbot, 2020a).

## Conclusion

In this chapter I have reflected upon some of my experiences, and personal lessons learned, during my time as a researcher investigating online communication around EDs. Online communication can play a vital role in the lives of individuals experiencing EDs, and awareness of this is growing within academic and professional contexts. Despite this, negative stigma is still common amongst the mass media and general population. Individuals with EDs still report feeling misunderstood. Qualitative and mixed-methods approaches can provide positive methods to help raise understanding and awareness. In turn, this can help to develop a shared language and identify positive approaches to treatment, more effective support mechanisms and appropriate non-shaming public health messages.

I hope the insights I have shared are helpful, or at least provide some food for thought! That said, if working in research has taught me anything, it is that every day is a lesson—and I am under no illusion that I have many more to learn in the future! The online research environment is a challenging but rewarding one—with an abundance of research opportunity. As responsible researchers we should strive to use appropriate study designs, keep up to date with ethical issues, and involve those with lived experience whenever possible. Research is a continuous learning process and by sharing our experiences more openly we can help to contribute to an ever-stronger body of knowledge.

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**Commented [CB1]:** AQ: I adjusted the wording here, as logically if you say 'under no illusion' then you need to say what the illusion is - here, the illusion is that you have nothing more to learn. Please check that this works for you, or feel free to suggest a different wording.

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