Supporting mental health professionals in making decisions about disclosure of lived experience: Acceptability and preliminary outcomes of a guided self-help intervention.

Anna Hildebrand

D.Clin.Psy. Thesis (Volume 1), 2018

University College London

UCL Doctorate in Clinical Psychology

Thesis declaration form

I confirm that the work presented in this thesis is my own. Where information has

been derived from other sources, I confirm that this has been indicated in the thesis.

Signature:

Name: Anna-Elsa Hildebrand

Date: 25/06/2018

1

Overview

People with concealable stigmatised identities, such as those who experience mental health problems, LGBTQ+ individuals, and people with certain infections or chronic diseases, are regularly faced with the decision of whether or not to disclose to others around them, as disclosure can have both positive and negative outcomes.

Research suggests that this decision is also one faced by many mental health professionals, who are often reluctant to disclose their own lived experience of mental health problems within their professional circle and workplace. Reluctance to disclose has been associated with fear of negative consequences, shame and stigma. Whilst the impact of stigma on disclosure has been explored in the literature, it has been less clear what the evidence suggests with regards to the effects of disclosure on self-stigma. The purpose of this thesis was to gain a better understanding of the effects of disclosure on self-stigma, and to develop an intervention to support mental health professionals with lived experience in carefully weighing up disclosure decisions.

This volume is comprised of three parts. Part one is a literature review which set out to explore the literature on the impact of disclosure on self-stigma in people with a concealable stigmatised identity (people living with human immunodeficiency virus [HIV]).

Part two consists of an empirical paper of a study which aimed to: a) adapt an existing group intervention into a guided self-help intervention for mental health professionals with lived experience to support them in making disclosure-related decisions in ways that are personally meaningful, and b) to evaluate the acceptability and preliminary outcomes of the adapted intervention.

Part three presents a critical appraisal of the research process, including personal reflections and an exploration of challenges that arose, and expands upon the discussion in the empirical paper in terms of study limitations and implications.

This was a joint project with Harriet Mills (see Appendix A).

Impact statement

The findings of the systematic literature review, part one of this volume, suggested that in suitable contexts, disclosure of a concealable stigmatised identity, such as HIV-positive status, can have several positive effects on the discloser. This seems especially true in peer group settings and specialist services such as HIV clinics. However, peer support spaces are often not available in places where people with HIV and other concealable stigmatised identities tend to come together, such as schools, universities and workplaces. One implication is that people with HIV and other concealable stigmatised identities may benefit from being able to access safe and meaningful peer support spaces.

The review also highlighted that prejudice and stigma can contribute to negative reactions from recipients of a disclosure and from non-specialist services with less training in the relevant area. Contact interventions delivered by educators or advocates might be one way of delivering appropriate training and reducing stigma. It would be helpful for future research to look more closely at contextual factors which increase the likelihood of disclosure having a positive effect on self-stigma. Additionally, the review proposes that the field of stigma research would benefit from more a consistent use of terminology and self-stigma measures as the variety of measures used to date make it difficult to compare results between studies.

The empirical paper, part two of this volume, describes a study of a newly adapted, guided self-help intervention aimed at supporting mental health professionals with lived experience in carefully reaching disclosure-related decisions. The study indicates that most participants valued and benefitted from at least some parts of the intervention. Participants who provided qualitative feedback suggested several improvements to the intervention and its evaluation, and noted the value of the peer support forum, part of the intervention. This is in line with the findings of the literature review outlined above. However, due to the limited sample size and limitations of the outcome measures used, further research is required to explore the outcomes of the intervention.

The study findings suggest that mental health professionals do not tend to disclose to colleagues, supervisors or managers. Therefore, it might be helpful to consider how a culture shift in the workplace could be brought about in order to support openness and encourage mental health professionals to access support in times of need. Greater collaboration between employers, researchers and professional and regulatory bodies might help work towards a common goal of changing the workplace climate with regards to disclosure of mental health problems.

Table of Contents

Overview	2
Impact statement	3
Table of Contents	5
Tables and Figures	6
Acknowledgements	7
Part 1: Literature Review	8
Abstract	9
Introduction	10
Method	14
Results	18
Discussion	40
References	50
Part 2: Empirical paper	64
Abstract	65
Introduction	66
Method	72
Results	87
Discussion	102
References	110
Part 3: Critical Appraisal	118
Overview	119
Reflections on the personal impact of the research	119
Challenges in the research process	121
Reflections on study findings and implications	126
References	129
Appendices	132
Appendix A: Outline of each trainee's contribution to joint project	133
Appendix B: Literature Review Quality Appraisal Scores	135
Appendix C: UCL Ethical Approval Letter	137
Appendix D: Information Sheet	139
Appendix E: Consent Form and Brief Screening	144
Appendix F: Participant Email Flowchart	147
Appendix G: HOP-MHP guide cover and contents pages	150
Appendix H: Participants' descriptions of their mental health problems	155
Appendix I: Additional quotes regarding the acceptability of the intervention and	
measures	158
Appendix J: Means (SDs) and statistics from the analysis of the original data	164

Tables and Figures

List of Tables

Part 1: Literature Review	
Table 1: Search terms	15
Table 2: Overview of articles included in review	19
Table 3: Measures of self-stigma and disclosure used in quantitative studies, and	
assessment of the relationship between them	31
Table 4: Questions used in qualitative and mixed method studies	34
Part 2: Empirical Paper	
Table 1: Demographics*	78
Table 2: Means (SDs) and statistics for ITT ANOVAs	100
List of Figures	
Part 1: Literature Review	
Figure 1: Study selection process	17

Acknowledgements

Firstly, I would like to thank my thesis supervisors, Dr Katrina Scior and Dr Henry Clements, for all your support and guidance. Thank you for always taking the time to provide feedback, and for guiding this project with your knowledge and experience. I would also like to thank Harriet for being a fantastic thesis buddy and for sharing this rollercoaster journey with me. Thank you to Laurie for her assistance and contributions throughout the project, and to Ashley for providing the brilliant artwork for the HOP-MHP guide.

Thank you to all my friends and family who cheered me on and dedicated time to proofreading my thesis, and to other trainees who made this journey feel less daunting. I would also like thank everyone who helped me on the long path to starting my training as a clinical psychologist by providing the practical and emotional support which allowed me to pursue this opportunity.

Finally, I would like to thank all stakeholders and participants who joined our research study, without whom the project would not have been possible.

Part 1: Literature Review
The effect of disclosure on self-stigma in people living with HIV: a systematic review

Abstract

Aims This review aimed to determine the impact of disclosing one's concealable stigmatised identity on self-stigma, specifically in people who are HIV-positive. The secondary aim was to consider how generalisable the findings are to people with other concealable stigmatised identities.

Method A systematic search was conducted using four electronic databases (PsycINFO, Medline, CINAHL Plus and Web of Science) to identify qualitative and quantitative studies investigating the relationship between disclosure and self-stigma in people with a concealable stigmatised identity aged 16 or over, published between 1970 and 2017. Due to the high number of results returned, it was decided to only include studies with participants who are HIV-positive.

Results The majority of quantitative studies identified a significant relationship between disclosure and self-stigma in people living with HIV. Several studies found an association between higher levels of disclosure and lower levels of shame and self-stigma but the cross-sectional nature of most quantitative studies limited conclusions about causality. Qualitative studies indicated that disclosure improved participants' self-perception, self-worth and self-acceptance, decreased shame and helped participants develop a more integrated sense of identity. However, positive disclosure outcomes appeared to depend on the context, with peer support settings being the most favourable and validating settings for disclosure. Negative reactions from disclosure targets seemed the main factor in disclosure having a negative impact on self-stigma.

Conclusion This review suggests that disclosure can have a positive impact on self-stigma in suitable settings. Limitations, implications and suggestions for future research are discussed.

Introduction

Concealable stigmatised identities can be defined as identities which are devalued due to the negative beliefs society holds about them, and that can be hidden from other people (Quinn & Earnshaw, 2013). Goffman (1963) originally made the distinction between people with 'discredited' identities whose stigma is visible or known to others, and people with 'discreditable' identities who are able to conceal their stigmatised attributes (but may become discredited if others discover these), suggesting that their experience and management of stigma differs on this basis. Groups of people with concealable stigmatised identities include people with mental health problems, people living with certain illnesses or infections such as Human Immunodeficiency Virus (HIV), and LGBTQ+ individuals (Pachankis, 2007). People with a concealable stigmatised identity may internalise the public stigma and discrimination they experience, leading to self-stigma (Vogel, Bitman, Hammer, & Wade, 2013) which can contribute to poorer health and social outcomes (Lee, Kochman, & Sikkema, 2002; Simbayi et al., 2007).

Stigma and self-stigma

The word *stigma* refers to a process whereby society views some individuals or groups as possessing disreputable and shameful attributes or characteristics, thereby leading to these individuals or groups being discriminated against or rejected (Goffman, 1963; Stutterheim et al., 2012). Exposure to recurrent stigmatising narratives in the media perpetuates negative attitudes and behaviour towards people believed to belong to a stigmatised group (Smith, Zhu, & Fink, 2017; Stuart, 2006). This can lead to verbal or physical abuse (Dinos, Stevens, Serfaty, Weich, & King, 2004; Dlamini et al., 2007), discrimination in the workplace (Jones & Williams, 2015) and in healthcare (Thornicroft, Rose, & Kassam, 2007), and to being avoided, disrespected and socially excluded (Karamouzian, Akbari, Haghdoost, Setayesh, & Zolala, 2015).

Repeated exposure to public stigma and discrimination can lead some people to start accepting the underlying prejudiced beliefs as true about themselves and to integrate them into their sense of self (Corrigan, Kosyluk, & Rüsch, 2013; Corrigan & Rao, 2012; Vogel et al., 2013), often referred to as 'self-stigma' or 'internalised stigma'. Self-stigma has been found to have detrimental effects on quality of life (Rüsch, Corrigan, Todd, & Bodenhausen, 2010), self-esteem (Rüsch et al., 2006), help-seeking or service engagement (Meacham, Orem, Nakigudde, Zujewski, & Rao, 2016) and mental health problems (Rael & Davis, 2017).

One condition that is stigmatised around the globe is HIV-positive status, which can be considered concealable unless an individual has reached a more advanced stage of HIV infection with visible symptoms. A recent report by the Joint United Nations Programme on HIV/AIDS (UNAIDS) highlighted the ongoing negative attitudes and discrimination experienced by people living with HIV in all areas of society, despite long-term campaigns which have tried to tackle this, causing (potentially) affected individuals to avoid HIV testing, seeking support and information, and adhering to treatment which in turn has a negative impact on HIV prevention (UNAIDS, 2017). Self-stigma is frequently experienced among people living with HIV (Lee et al., 2002) and can have negative effects on mental health (Vyavaharkar et al., 2010), social support (Mak et al., 2007), and physical health, for example by negatively impacting upon engagement with medical treatment or antiretroviral therapy (ART) adherence (Earnshaw, Smith, Chaudoir, Amico, & Copenhaver, 2013).

People with stigmatised identities manage and respond to stigma in different ways, and strategies include withdrawal from social situations (Stutterheim et al., 2012), concealment of one's stigmatised identity (Bril-Barniv, Moran, Naaman, Roe, & Karnieli-Miller, 2017), seeking peer support (Schwartzberg, 1994), controlled disclosure to supportive others, and becoming an educator (Rael et al., 2017; Van Der Straten, Vernon, Knight, Gómez, & Padian, 1998). Individuals with concealable

stigmatised identities in particular therefore regularly face the decision of whether or not to disclose their identity in different contexts and with different people (Pachankis, 2007), and have to weigh up a range of potential positive and negative consequences (Corrigan et al., 2009). The consequences of disclosure are explored in more detail below.

Disclosure

Factors which influence the decision of whether or not people feel able to disclose a concealable stigmatised identity in different settings include: self-stigma, with higher levels of self-stigma being associated with lower rates of disclosure (Overstreet, Earnshaw, Kalichman, & Quinn, 2013; Tsai et al., 2013); anticipated stigma, fear of social rejection and the disclosure target (Grice, Alcock, & Scior, 2018); past experiences of discrimination (Ragins, Singh, & Cornwell, 2007); and the anticipated benefits (e.g. gaining adjustments, being a role model) versus feared costs of disclosure such as fears of being unable to get a job and being discriminated against in the workplace (Brohan et al., 2012) or being blamed and abandoned (Moyer, Igonya, Both, Cherutich, & Hardon, 2013).

The actual outcomes of disclosure are hypothesised to depend on factors such as disclosure motivations and goals which in turn influence the content of one's disclosure and the reaction of the disclosure target person (Chaudoir & Fisher, 2010; Chaudoir, Fisher, & Simoni, 2011). The literature around disclosure outcomes is mixed (e.g. Stutterheim et al., 2011), with some evidence that disclosure can result in increased social and emotional support (Smith, Rossetto, & Peterson, 2008; Weisz, Quinn, & Williams, 2015; Wong et al., 2009) and improved treatment retention and adherence (Stirratt et al., 2006; Wohl et al., 2011), and that higher perceived benefits of disclosure are linked to greater quality of life and sense of empowerment (Corrigan et al., 2010). Additionally, interventions that support people to carefully reach disclosure-related decisions have been associated with a reduction in the more harmful aspects of self-stigma and stigma stress (Corrigan et

al., 2015; Mulfinger et al., 2018; Rüsch et al., 2014). On the other hand, disclosure has also been associated with increased victimisation and physical attacks resulting in poorer mental health (D'Augelli & Grossman, 2001). Outcomes seem to depend on contextual factors; for example, disclosing to a suitable person in the right context appears to be associated with more positive outcomes (Lam, Naar-King, & Wright, 2007).

Although higher levels of self-stigma have been associated with poorer health outcomes and self-stigma has been identified as a factor influencing disclosure decisions, it is unclear what the evidence suggests regarding the effect of disclosure on self-stigma. At present, there is no published systematic literature review examining the effect of disclosure on self-stigma in people with a concealable stigmatised identity. Given the harmful effects of self-stigma, and the development of several disclosure decision interventions in recent years, some of which are aimed at reducing self-stigma (Corrigan et al., 2015; Mulfinger et al., 2018; Rüsch et al., 2014), it seems relevant to synthesise and critically appraise the literature in this field.

Aims and Objectives

The review set out to answer the following question: How does disclosure of a concealable stigmatised identity affect self-stigma or sense of self in people who are HIV-positive?

It was hoped that the findings would help draw some conclusions about how people who are HIV-positive can be better supported to make successful, beneficial disclosures which could positively impact upon their health and wellbeing. In addition, it was anticipated that the findings might prove helpful to researchers in identifying useful directions for future research in this topic area, as initial scoping searches revealed a lack of consistent terminology and methodology (including outcomes measures used) in the current literature.

Method

Search strategy

A systematic literature search was conducted using the following electronic databases: PsycINFO, Medline, CINAHL Plus, and Web of Science (Core Collection - Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index, Emerging Sources Citation Index). The search included terms relating to the following concepts: self-stigma, disclosure and concealment, and HIV status (see Table 1 for a full overview of the search terms).

The search was restricted to empirical papers published in peer-reviewed journals in the English language between 1980 and 2017, and to relevant age groups where those filters were available (e.g. adolescence onwards). The year 1980 was chosen as a start date because it was during the 1980s that public health agencies and researchers first began to identify HIV infection (then known under a range of different names, see terms included in Table 1) as a global phenomenon (Avert, 2018), and scoping searches indicated that the first studies related to the search terms used in this review were published in this decade.

The terms listed in each column were combined with the Boolean operator 'OR' resulting in three search strings which were then combined with the Boolean operator 'AND' to search titles and abstracts that included the relevant search terms.

Inclusion criteria

- Empirical studies, published in a peer reviewed journal;
- Articles written in the English language;
- Population: Participants aged 16 and over who are HIV-positive, including
 participants who self-identify as HIV-positive, and are not described as having
 visible symptoms or illnesses associated with advanced HIV infection (to meet
 criteria for a concealable stigmatised identity).

Table 1
Search terms

Aspects of self-stigma	Management of concealable identity	Type of concealable stigmatised identity
Self-stigma	Disclosure	Human immunodeficiency virus
Internalised* stigma	Disclosing	HIV
Self-acceptance	Disclose	Acquired Immune Deficiency Syndrome
Self-perception	Self-disclosure	AIDS
Sense of self	Secrecy	Lymphadenopathy Associated Virus
Shame	Coming out	LAV
Internalised* homophobia	Concealment	Gay-Related Immune Deficiency
	Concealing	GRID
	Conceal	HTLV
	Coping	HTLV-III

^{*} Both UK and US spellings were entered into the search

- Intervention/Phenomenon of Interest: Voluntary disclosure of HIV diagnosis in any setting or context by the affected individual (e.g. to family, friends, peer group or therapy group, in the workplace). This should be a setting that involves some form of active disclosure.
- Comparator: not applicable.
- Outcomes: Positive or negative effects of disclosure on participants' self-stigma,
 broadly including concepts such as self-perception, sense of self, (internalised)
 shame and self-acceptance.
 - Articles had to report findings on the relationship between disclosure and self-stigma, and this had to be a clear theme or main outcome of the study (i.e. not just mentioned in passing).
 - Articles reporting correlational findings were included.
- Study design: Qualitative, quantitative and mixed method designs were included.

Exclusion criteria

Single case reports or first-person narratives

Assessment of study and article quality

The protocol developed by Hawker, Payne, Kerr, Hardey, & Powell (2002), was used to assess the quality of the eligible studies and the quality of the articles reporting these studies. This tool was chosen because it can be applied to both qualitative and quantitative study designs. Two researchers independently completed the quality assessments by considering the nine areas outlined in the protocol. Each area was rated as either very poor (1), poor (2), fair (3) or good (4). A total score of between 9 (very poor) and 36 (good) can be achieved. The nine areas assessed by this tool include: abstract and title, introduction and aims, method and data, sampling, data analysis, ethics and bias, results, transferability or generalisability, and implications and usefulness. Inter-rater reliability was assessed.

Study selection and method of synthesis

The systematic searches of the four databases identified 736 articles (excluding 237 duplicates identified using Excel). After screening the titles and abstracts of these articles, the selection was narrowed down to 70 articles for which full text copies were retrieved. The 70 studies were assessed for eligibility by two independent raters, with any disagreements resolved through discussion and input of a third independent rater, arriving at a final selection of sixteen studies which were included in this review. Figure 1 provides an overview of the study selection process and reasons for study exclusions. Due to the high level of heterogeneity in the data reported by the quantitative studies included in this review, a statistical synthesis was not considered suitable. The synthesis method included a narrative summary of the evidence and also drew on principles of descriptive reviews (e.g. in terms of extracting certain characteristics and pieces of information from each study, as demonstrated in the results tables, which facilitated the narrative summary of overall

trends and methodological issues identified in the data) and critical reviews, for example by using a quality appraisal instrument to evaluate the overall quality, strengths and weaknesses of research in this area (Paré & Kitsiou, 2016).

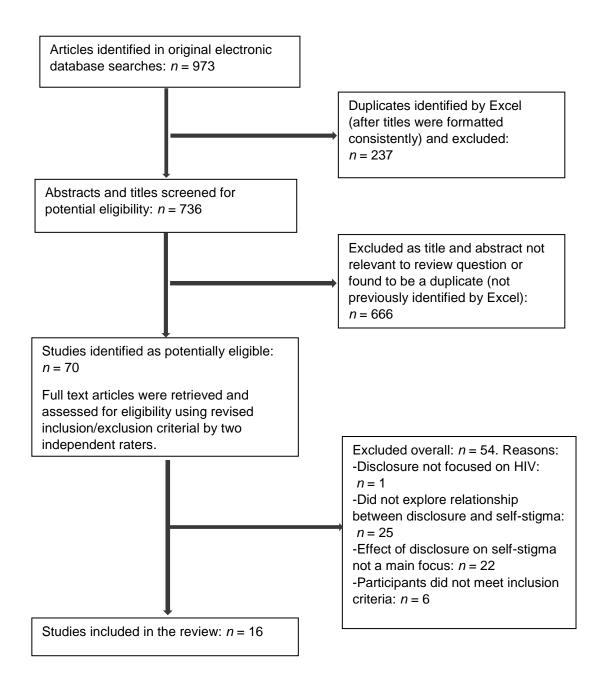


Figure 1: Study selection process.

Results

Of the 16 articles included in the review, eight were qualitative studies, seven quantitative studies and one a mixed methods study. All but one of the studies were conducted between 2002 and 2017, with the remaining study conducted in 1998.

The studies were carried out in a variety of locations. Eight of the studies took place in the USA, although two of these did not clearly specify their study locations so this was assumed based on where the researchers were based. One study was carried out in each of the following countries: Canada, China, Italy, Netherlands, Tanzania and UK. One study was conducted across three African countries: Ethiopia,

Mozambique and Uganda. Finally, one study recruited participants from 20 countries across eastern and southern Africa and the Asia-Pacific region including: Australia,

Botswana, Guam, Hong Kong, India, Indonesia, Japan, Kenya, Malaysia,

Singapore, South Africa, Swaziland, Taiwan, Tanzania, Thailand, the Philippines,

Uganda, Vietnam, Zambia, and Zimbabwe, although many of these countries were represented by just a single participant. Table 2 below provides an overview of the key features and findings of each study as well their overall quality appraisal score.

The remainder of the results section explores strengths and limitations of the included studies which affect the conclusions that can be drawn, provides a brief description of the quality appraisal process, examines how the key concepts of disclosure and self-stigma were measured in the qualitative and quantitative studies, and evaluates the findings of the reviewed studies in relation to the research questions in the context of their methodological strengths and weaknesses.

Table 2

Overview of articles included in review

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality assessment score
Qualitative Studies				
Buseh & Stevens (2007) USA (Wisconsin)	 2-year longitudinal qualitative study N=29 HIV+ African American women Community-based purposive sampling Ten 2-3-hour interviews with each participant 	 Internal stigma experienced as existential despair, shame and self-blame Stigma experienced at all levels – internal, social and institutional/structural 	Through disclosing to peers in support groups and becoming public advocates or educators, the women were able to overcome negative feelings about themselves (e.g. shame, guilt)	32
Donnelly et al. (2016) Canada (Vancouver, British Columbia)	 Community based participatory research framework N=33 from Aboriginal, Latino, Asian and African communities Five peer-facilitated focus groups 	 Internalised stigma as poor self-worth, internalised shame, guilt and self-blame Impact on sense of self 	 Effect of disclosure on self-stigma depends on reaction from others Negative reactions resulted in reinforcement of individual's negative self-perceptions Negative reactions of service providers can be shaming and reduce access to services Double or triple stigma related to participants' ethnicities and other demographic factors further increased marginalisation and obstacles to accessing services 	32

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality assessment score
Frye et al. (2009) USA (Baltimore, Miami, New York, San Francisco)	 N=116 HIV+ injection drug users who had taken part in a larger HIV prevention intervention trial (68 in the experimental arm, 48 in the control arm) Qualitative interviews were conducted post-intervention in 2005 lasting 45-90 minutes Taking part in the programme involved publicly identifying as HIV+ to their group 	Did not explore participants' experiences of self- stigma, only mentioned this in context of how the intervention / disclosure alleviated self-stigma	 Disclosure linked to feeling comfortable with oneself Being around other people who had disclosed and were accepting of their status made participants more comfortable with disclosing which helped them feel more self-accepting of their HIV-positive status Participation in the intervention group helped some people disclose more outside of the group which in turn increased their sense of comfort with being HIV-positive and reduced feelings of shame. This helped them develop roles as educators, offering information and hope to other people 	31
Holt et al. (1998) UK (Northern and Yorkshire Region)	 Recruitment through targeted advertising (e.g. posters in research centres and the local gay scene) and in collaboration with staff voluntary HIV/AIDS centres N=40 gay and bisexual men, mean age 34 years Data collection through brief demographics questionnaire and semi-structured interviews 	Self-stigma experiences not directly explored, only mentioned in relation to impact of disclosure on shame, guilt and self-acceptance	 Participants linked being open about their HIV-positive status to lower feelings of shame, increased self-acceptance However, the authors also noted that disclosure sometimes resulted in negative outcomes, for example when a negative response by a potential sexual partner left the discloser feeling worse about themselves 	28

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Machtinger et al. (2015) USA (San Francisco)	 Purposive sampling N=8 women who had completed an expressive therapy group intervention Conducted semi-structured interviews about participants' experiences of taking part in the workshops and public theatre performance 	HIV-related self- stigma mostly mentioned in the form of shame	 Sharing painful experiences related to HIV helped participants feel relieved of feelings of shame and guilt, and increase their self-acceptance by developing a stronger, more positive sense of identity Some participants reported feeling more confident in publicly sharing their experiences and wanting to continue to educate people about HIV 	32
Norris & DeMarco (2005) USA (not clearly stated, authors based in USA, at Boston College, Massachusetts.)	 N=4 African American women One focus group of around 50 minutes duration following the film intervention. 	 Concepts related to self-stigma mentioned sporadically, e.g. negative self-image, self-blame 	 Speaking about their experiences on film was validating and freeing, and helped the women feel more self-accepting despite challenges of reflecting on painful experiences Field notes indicated that the women benefitted from being able to share their stories with other women in the group and that this strengthened their sense of self-worth 	25
Parsons, VanOra, Missildine, Purcell & Gomez (2004) USA (New York City and San Francisco)	 N=158 male and female injection drug users Recruitment in healthcare and community services accessed by this population Used qualitative interviews and quantitative survey but this article focused on qualitative data only 	Self-stigma experiences not directly explored, only mentioned in relation to disclosure	 Timing of disclosure seems important – of 39 participants who reported disclosing their HIV status to their primary partner <i>after</i> having sex with them, 35 reported negative consequences which they perceived as worse than if they had disclosed earlier on in the relationship Other participants reported a more positive sense of identity following disclosure 	34

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Paxton (2002) 20 countries in eastern and southern Africa and the Asia-Pacific region	 N=75 (43 females, 32 males) Recruitment in-country and at AIDS conferences or other HIV-related forums; used snowballing technique starting with the author's network Data collection through interviews 	Self-stigma describes as shame and worthlessness	 Interviewees across different regions and cultures reported a sense of pride, feeling good about themselves, feeling like they had done something worthwhile, feeling stronger, more self-confident and empowered, and less ashamed after speaking out (e.g. as community AIDS educators) This was despite some negative consequences of speaking out such as discrimination or rejection 	25
Quantitative Studies				
Emlet (2006) Pacific Northwest. Researcher based in Tacoma, Washington State, USA.	 Purposive sampling technique to target older adult group N=88 (44 aged 20-39, 44 aged 50+ described as 'older adults'); matched case control design Recruitment & structured interviews conducted in collaboration with an AIDS Service Organisation 	Self-stigma measured as part of a 13-item HIV stigma scale developed by Sowell et al. (1997) with some items assessing shame and self-blame, rated either 1 (not at all), 2 (rarely), 3 (sometimes) or 4 (often)	 50% of older adult group and 46% of younger adult group reported (sometimes or often) feeling ashamed about their HIV-positive status 27% of older adult group and 41% of younger adult group reported (sometimes or often) feeling that their illness was a punishment for things they had done in the past Differences between groups on these items were not significant Identified overall tendency for older adults to disclose less frequently across a range of settings (including partners, friends, neighbours, church members, and healthcare professionals) Small, non-significant negative correlation between disclosure and overall stigma score 	32

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Geary et al. (2014) Ethiopia, Mozambique & Uganda – three to four locations in each country (rural and urban)	 Snowball recruitment technique with assistance from organisations and groups providing support for people who are HIV+ N=862, mean age 32.8 years Data collection in collaboration with research teams based in each country 	Self-stigma assessed using five items from the 'internalized AIDS-related Stigma Scale' (Kalichman et al., 2009; Simbayi et al., 2007), asking about shame, guilt, sense of worthlessness and difficulties disclosing to others.	 Women had higher mean self-stigma scores than men (n.s.), and in both genders higher levels of self-stigma were related to poorer perceived health More men than women disclosed their illness to their spouse/partner. Disclosure to spouse was associated with more positive health perceptions in women only Involvement in a support group and disclosing to one's partner were associated with lower self-stigma Belonging to a support group was not associated with better health outcomes 	35
Heggeness, Brandt, Paulus, Lemaire & Zvolensky (2017) USA (Southwestern Texas)	 Used cross-sectional baseline data from a larger project testing the effectiveness of an anxiety intervention for people living with HIV Participants in original study recruited through flyers at local HIV/AIDS services N=80 (mean age 48; 61.2% male, 37.5% female, 1.3% transgender) 	 Assessed self-stigma using the negative self-image subscale of the 'HIV/AIDS Stigma Scale' (HASS) (Bunn, Solomon, Miller, & Forehand, 2007). The subscale includes questions around internalised shame and guilt. 	 Negative correlation between the negative self-image subscale (HASS-N) and disclosure Negative self-image predicted HIV disclosure, whilst emotion dysregulation did not have a moderating role 	33

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Li, Hsieh, Morano & Sheng (2016) China (Beijing)	 Cross-sectional survey N=266 men who have sex with men (MSM) Convenience sample - recruited through referrals from staff at a non-governmental organisation based at a hospital providing healthcare and other services for people with HIV 	Self-stigma measured with the negative self-image subscale of the 'HIV Stigma Scale' (Berger, Ferrans, & Lashley, 2001), with items such as "Having HIV makes me feel I'm a bad person" and "I never feel ashamed of having HIV (reverse)"	 Disclosed HIV status was not associated with the negative self-image subscale Parts of study findings difficult to interpret based on information provided 	31
Lyimo et al. (2014) Northern Tanzania (Kilimanjaro region)	 Used data from a study conducted in 2010 at two rural antiretroviral treatment clinics N=158 Trained research assistants conducted 30-minute, face-to-face interviews using structured questionnaires plus follow-up visits 	Self-stigma was measured using five translated items from the 'HIV stigma scale' (Berger et al., 2001) and the 'internalized AIDS-related Stigma Scale' (Kalichman et al., 2009).	 53 participants (34%) scored high to very high on self-stigma, while 9 (6%) reported no self-stigma Nine participants (6%) reported not having disclosed to anyone, whilst 130 (82%) reported having disclosed to a family member. Marital status affected disclosure to spouse versus partner Voluntary disclosure significantly predicted self-stigma when controlling for demographic variables and treatment factors (e.g. side effects) Distinguished between voluntary and involuntary disclosure and found distinct patterns in their relationships with self-stigma and perceived stigma 	27

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Prati et al. (2016) Italy	 Recruitment via social events and networks, online videos and advertisement and with assistance from The Italian League for the Fight against AIDS (LILA). N = 387 HIV+ participants and 6074 HIV uninfected participants Participants completed an anonymous online questionnaire 	Measured self-stigma using 11 items adapted to Italian language in a previous study which were partly based on previous instruments (e.g. Sayles et al., 2008; Visser, Kershaw, Makin, & Forsyth, 2008)	 Found negative association between self-stigma and disclosure of HIV-positive status Self-stigma predicted disclosure of HIV status in mediation analysis Disclosure of HIV-positive status was, in turn, the only significant predictor of positive health behaviours (i.e. engagement in care) Personal knowledge of someone who is HIV-positive (in-group contact) can reduce self-stigma and thereby make disclosure less difficult 	31
Swendeman, Rotheram-Borus, Comulada, Weiss & Ramos (2006) USA (Los Angeles, San Francisco & New York City)	 Recruitment from 20+ HIV/AIDS-related services, organisation and outreach programs as well as advertisement and announcement in the community Data from N=147 substance- using young people included in the analysis, taken from a previous larger intervention trial Data collection via protocol- based interviews and computer-assisted self- interviews 	• Used the term perceived stigma to encompass "fear or anticipation of discrimination and rejection, and internal sense of shame". This was assessed using seven items adapted from Sowell et al. (1997), including three items that form a 'shame dimension', rated on a 4-point Likert scale ranging from not at all (1) to often (4).	 73% of participants scored between 'rarely' (2) and 'often' (4) on at least one item on the shame dimension A higher proportion of family and friends being aware of the participant's serostatus levels was associated with lower levels of shame 	34

Table 2 (continued)

Author(s), year, and country / region	Sampling and methodology	Experience of self-stigma	Key findings regarding effect of disclosure	Total quality appraisal score
Mixed methods				
de Vries, Koppen, Lopez & Foppen (2016) Netherlands	 Stratified research sampling technique – attempted to represent population characteristics Recruitment via networks of trained peer interviewers and snowball sampling, treatment centres, and HIV-related organisations N=468, surveyed as part of a larger project Mixed methods structured survey (179 questions, 41 open-ended) administered by trained peers lasting 2-3 hours 	 26% experienced self- stigma Self-stigma described as 'feelings of worthlessness' 	 Article reported findings on sub-set of questions around stigma and self-management 60% indicated using selective disclosure as a self-management strategy 70% of survey respondents reported that they felt stronger after disclosing their HIV status Qualitative data indicated that participants felt more confident, relieved, liberated, more self-accepting and able to be themselves by integrating their HIV-positive status into their identity following disclosure Small, positive correlation between feeling stronger and 'becoming an activist' 16% of participants who indicated they had never disclosed had higher scores on self-stigma measure than (selective) disclosers 	33

Quality appraisal

The quality appraisal scores for each study included in this review are presented in Appendix B, including scores for each of the nine categories of the protocol and an overall appraisal score. All studies were independently rated by the same two researchers. Intra-class correlations (ICC) with 95% confidence interval (CI) were calculated using SPSS version 22, based on an average measure, absolute agreement, two-way mixed effect model, as a measure of inter-rater reliability. Inter-rater reliability was high, with ICC = .941, 95% CI: .783, .981, p < 0.01. All but two studies were rated as 'fair' or above (minimum of 27 points), whilst two were rated as 'poor' at 25 points each. None of the studies attained a 'good' rating (the maximum score of 36 points), and none were rated as very poor. Several studies showed room for improvement in how they addressed ethics and bias, and a few studies did not adequately address transferability and generalisability to a wider population and did not provide sufficient information about their sampling strategy. Overall strengths of the included studies relate to the presentation of results and provision of a good introduction.

Critique of the current evidence base

Several shortcomings were identified in the set of qualitative and quantitative studies. One limitation relevant to both qualitative and quantitative studies concerns the studies' sampling strategies. As can be seen in Table 2, several of the studies targeted specific groups (e.g. women/African American women, injecting drug users or substance users, gay and bisexual men, or men who had sex with men). Many of these specific groups experience multiple layered stigma associated with other aspects of their identity and their experiences may well be influenced by these multiple stigmatised identities. Whilst these studies provide valuable information about the specific groups of people studied, they are less transferable between groups or to the general population. This makes it difficult to extract generalisable conclusions from the literature. In addition, it was mostly unclear what stage of HIV

infection participants were at, and when studies did measure this, data from all participants were usually presented together. One study (Holt et al., 1998) did present data separately for those immediately post-diagnosis, in the asymptomatic phase, and in the symptomatic and AIDS phases. However, a proportion of the people in the third group were still able to conceal their HIV-positive status. All relevant data from studies where it was difficult to separate out people with visible symptoms was included which may have resulted in some of the findings of this review being influenced by data from individuals who were unable to conceal their HIV status. The results of the mixed method study (de Vries et al., 2016) may be mentioned in the findings from both qualitative and quantitative studies included in this review.

Qualitative studies.

Sample size varied across the eight qualitative studies, with the smallest samples consisting of four and eight participants and the largest sample comprising 158 participants. In addition, two of the studies (Buseh & Stevens, 2007; Machtinger et al., 2015) employed purposive sampling techniques where participants are selected based on certain characteristics. For example, Buseh and Stevens (2007) recruited participants with the aim of increasing the likelihood that they would provide in-depth accounts about their experiences of living with HIV and HIV stigma and participants self-selected for the study by contacting the researchers. Whilst this is a frequently used technique which allows researchers to collect rich information about specific phenomena, it may cause selection bias and affect how representative the sample is of the wider population. In this instance, participants who self-selected for the study may have been those who had more opportunity for prior reflection on their experiences or who had a more positive and confident attitude toward disclosure and resisting stigma in the first place. Most of the studies recruited through healthcare or community-based organisations, which might mean

that participants have better social and peer support than those who struggle to access services, particularly in more rural areas. One study (Paxton, 2002) recruited participants who were often the first person in their country or area to have spoken openly about their HIV-positive status, and acknowledged that the sample was biased towards people who had spoken publicly about their status in the media.

Taken together, these factors mean that whilst the research provides valuable insights about the experiences of participants in these studies, it is more difficult to generalise the findings to a wider population whose context is likely to vary significantly from the samples included in many of these studies. Finally, most of the studies did not purely focus on disclosure and self-stigma and the findings are therefore drawn from small to moderate amounts of data from each study.

Quantitative studies.

Many of the limitations concerning the quantitative literature relate to the measures of self-stigma used, both in terms of the depth with which they examine this concept and the variability of measures used across studies. Some of the studies included only three to five items selected from various measures of self-stigma, whilst others used full sub-scales of HIV stigma measures. For example, one study (Swendeman et al., 2006) measured self-stigma as a sub-domain of perceived stigma using only three items adapted from Sowell et al. (1997), whereas Li et al. (2016) used the 'negative self-image' subscale of the HIV Stigma Scale (Berger et al., 2001) and Prati et al. (2016) used 11 items partly adapted from two previous scales to measure self-stigma. For a full overview of the measures of self-stigma used in the quantitative studies see Table 3. The variability of outcome measures used also made it difficult to compare or aggregate the results of these studies. For this reason, it was not appropriate to conduct a meta-analysis of the quantitative findings derived from this small number of studies. Another limitation of the quantitative studies reviewed is the cross-sectional nature of almost all of the

studies. Although one study (Lyimo et al., 2014) did collect data at several time points, this was focused on physical health outcomes such as medication adherence. Therefore, it is not possible to establish causation in terms of the effect disclosure and self-stigma have on each other in these studies, although considering the findings from quantitative studies in conjunction with the findings from qualitative research can help delineate the relationship more clearly.

The effect of disclosure on self-stigma

Findings regarding the effect of disclosure on self-stigma or the relationship between disclosure and self-stigma will first be presented for qualitative and then quantitative studies.

Findings from qualitative studies.

Six of the studies included in the review used interviews (mostly semi-structured although the type of interview was not always specified) and two used focus groups to collect data. Most articles did not provide a full list of questions used to collect data but provided an overview of the main topic areas and some example questions (see Table 4). It was noticeable that the example questions or main interview areas outlined in the articles did not directly focus on self-stigma except in one study (de Vries et al., 2016). Four articles mentioned asking direct questions about participants' experiences of disclosure. However, the participant data embedded in the results sections of the articles showed that either the broad, open ended questions allowed themes of self-stigma and disclosure to arise naturally, or that relevant questions were asked without this being mentioned in the articles.

Table 3

Measures of self-stigma and disclosure used in quantitative studies, and assessment of the relationship between them

Study author	Outcome measure(s) used	How the relationship between disclosure and self-stigma was assessed	Findings
Emlet (2006)	Self-stigma: Assessed as part of 13-item HIV stigma scale (Sowell et al., 1997) which includes items on feeling ashamed of one's illness and thinking the illness is a punishment for things one has done in the past. Items are not listed in the article. Items are rated either 1 (not at all), 2 (rarely), 3 (sometimes) or 4 (often), providing a total score between 13 and 52.	Bivariate correlations	Small, non-significant negative correlation (<i>r</i> = -0.189).
	Disclosure: Assessed using a disclosure inventory which asked participants whether they had disclosed their HIV-positive status to a range of individuals (e.g. spouses, health professionals). Each type of individual they had disclosed to was given a score of '1'.		
Geary et al. (2014)	Self-stigma: Assessed using five items from the Internalized AIDS-Related Stigma Scale (Kalichman et al., 2009), rated 1 agree (1), neutral (2) or disagree (3), including: I am ashamed that I am HIV positive. I sometimes feel worthless because I am HIV-positive.	One-way ANOVAs to compare mean self-stigma scores by gender, belonging to a support group (yes/no), having disclosed to spouse or partner (yes/no) and other variables	Self-stigma mean score comparisons for different variables (range 5 to 15, with higher mean score = higher level of self-stigma): 1. Gender
	Responses are reverse coded so that greater total scores indicate higher levels of self-stigma.		Females: 7.84, Males: 7.46 Difference n.s.
	Disclosure: Assessed by asking participants to whom they had disclosed their status, with a focus on spouses and sexual partners.		2. Belonging to a support group Yes: 7.49, No: 8.06 Significant at <i>p</i> < 0.01.
	Other relevant questions: Participants were also asked about their involvement in HIV-related activities such as support groups.		3. Disclosed to spouse / partner Yes: 7.49, No: 8.05 Significant at $p < 0.01$.

Table 3 (continued)

Study author	Outcome measure(s) used	How the relationship between disclosure and self-stigma was assessed	Findings
Heggeness et al. (2017)	Self-Stigma: HIV/AIDS Stigma Scale (HASS; Bunn et al., 2007): 32 items rated from 1 (strongly disagree) to 4 (strongly agree) comprising four stigma sub-scales, including a 'negative self-image' subscale (HASS-N).	Bivariate correlations	HIV disclosure and all four HASS subscales were significantly negatively correlated. The correlation between disclosure and HASS-N was $r = -0.32$ ($p < 0.01$).
	Disclosure: Participants were asked to report to how many people they had disclosed their HIV-positive status (nobody, hardly anybody, a few people, almost anyone, everyone).	Hierarchical regression- based moderation models, including one with negative self-image and emotion dysregulation as predictors and HIV disclosure as outcome.	Negative self-image was significantly associated with HIV disclosure ($\beta = -0.39$, $t = -3.01$, $p = 0.004$), whilst emotion dysregulation was not.
	Other: Participants were assessed for current psychological disorders, difficulties with emotion regulation, and positive and negative dispositional affect		
			Post-hoc analysis showed a pattern where negative-self-image was significantly related to disclosure when participants' emotion regulation scores were high.
Li et al. (2016)	Self-stigma: Measured using the HIV Stigma Scale (Berger et al. 2001) which has four subscales, including a Negative Self-Image subscale.	Linear regression analysis	Negative association (n.s.) between disclosed HIV status and negative self-image (β = -1.97, 95% CI: -3.96 to 0.02, $p \le$ 0.20)
	Disclosure: Measured HIV disclosure status and the people to whom participants had disclosed.		
Lyimo et al. (2014)	Self-stigma: This was assessed using 5 items translated from the HIV stigma scale (Berger et al., 2001) and the internalized AIDS-related stigma scale (Kalichman et al., 2009). The example item provided was 'I feel guilty because I have HIV'.	Stepwise regression analyses.	Voluntary disclosure predicted self-stigma (β = -0.39 , p < 0.005). The model fit was R^2 = 0.25 compared to a fit of R^2 = 0.11 when only demographic and treatment factors where included in the model.
	<i>Disclosure:</i> Voluntary disclosure was assessed by asking participants to whom they had disclosed their HIV-positive status besides staff at the treatment clinic, providing a list of 21 types of people.		

Table 3 (continued)

Study author	Outcome measure(s) used	How the relationship between disclosure and self-stigma was assessed	Findings
Prati et al. (2016)	Self-stigma: Assessed by 11 items translated into Italian language, partly based on previous instruments (e.g. Sayles et al., 2008; Visser et al., 2008). Items were rated from 1 (strongly disagree) to 4 (strongly agree). Sample items include: I feel ashamed that I have HIV I am concerned that if I am sick people I know will find out about my HIV	Correlations Mediation and moderation analyses; calculated κ^2 values to provide effect sizes for the mediation analysis	r = −0.55, p < 0.01 Self-stigma, but not personal knowledge of someone who is HIV-positive, predicted disclosure of HIV-positive status. The mediation analysis of the pathway of personal knowledge of someone who is HIV-positive to disclosure of
	• I grew as a person through having HIV (reverse) Disclosure: Participants were asked to indicate to what extent they had disclosed their status to different categories of people (e.g. family members, friends, colleagues) on a scale of 1 (nobody knows) to 4 (everyone knows).		HIV-positive status through internalised stigma demonstrated complete mediation, with a medium sized mediation effect of $\kappa^2 = 0.131$. Disclosure of HIV-positive status, in turn, significantly predicted positive health behaviours (i.e. engagement in care).
	Other: Participants' viral load and engagement in care were also assessed (uninfected participants were asked if they had ever been tested), and they were asked if they personally knew someone who is HIV-positive.		
Swendeman et al. (2006)	Self-stigma: Assessed as a component of perceived stigma (which the authors define as including an internal sense of shame) using three items adapted from Sowell et al. (1997), including items asking how often participants felt ashamed because they are HIV-positive or thought HIV was a punishment over the previous three months. Items are rated from 1 (not at	Multivariate linear regression	Full results not presented in text. A table provided the following data from the linear regression of perceived stigma, in terms of the relationship between the shame dimension and family and friends' serostatus awareness: $B = -0.20$, $SE = 0.11$, $p < 0.05$, $R^2 = 0.18$
	all) to 4 (often). Disclosure: Measured as the proportion of a participant's family and friends that is aware of their serostatus, ranging from 1 (none) to 4 (all).		Findings indicated that higher serostatus awareness among family and friends of a HIV-positive person was associated with lower levels of shame.

Table 4

Questions used in qualitative and mixed method studies

Study	Questions / tonic areas (relevant to review tonic)
Study	Questions / topic areas (relevant to review topic)
Buseh & Stevens (2007)	 Example questions from initial interviews (full list of questions not provided in article): How did you find out you have HIV? What was that like for you? What has happened since then? How has your life changed because of the HIV? How has HIV affected your family? How have others reacted to you?
	 Subsequent interviews focused on the following: Further exploration of the impact of living with HIV The context of participants' lives The most difficult things about living with HIV How participants responded to being discriminated against
Donnelly et al. (2016)	Focus group questions focused on five main areas. Relevant sample questions included:
	Concerns: What are the issues and/or concerns that come to your head when you meet somebody who does know about your HIV status? Why do you think that happens?
	 Interactions with healthcare providers: Have you disclosed your status? If yes, why, when, and to whom? If no, why? Did anybody do something that made you feel more comfortable about your HIV status? Like what?
	 Stigma: Have you ever experienced stigma/discrimination? If yes, how, when, and why? How do you define stigma? How do you understand the concepts of stigma, discrimination, and stereotyping? How do you think these associations, if any, relate to sexual orientation, ethnicity, and socioeconomic status? Why do you think there are such associations?
de Vries et al. (2016)	Included 41 open-ended questions in their survey; 25 of these included in the analysis. Items loaded onto three stigma scales: structural (two items), public (four items) and self-stigma (eight items). Sample questions included (translated from Dutch; more questions provided in the article):
	 Have you ever been rejected (education, work, or housing) because of your HIV status? Have you ever been ashamed because you got HIV? Do you feel guilty about it towards other people? Were you afraid people did not want to associate with you anymore? Did you think that getting HIV was a punishment for your own behavior? Did you think you should not be allowed to get kids because you have HIV? Did you ever feel appalled by yourself because you had HIV?

Study	Questions / topic areas (relevant to review topic)
Frye et al. (2009)	 A full list of questions was not provided. According to the article, interview questions focused on: The impact of the Intervention for Seropositive Injectors - Research and Evaluation (INSPIRE) study How participants (in the experimental condition) experienced the peer mentoring component and the impact of this HIV disclosure to friends, family, and sex partners (before and after the intervention)
Holt et al. (1998)	 A full list of questions was not provided. The semi-structured interviews encouraged exploration of the following areas: Participants' sexual health, specifically relating to service provision, personal and interpersonal issues How their sexual health and lifestyle had changed over time / since diagnosis The time around their diagnosis and life since the diagnosis The main stressors experienced in relation to the disease and how they had coped with these Positive and negative experiences of services (statutory and voluntary)
Machtinger et al. (2015)	 The interview guide focused on the following two main areas of participant's experiences of taking part in the project: Participants' experience of public disclosure of their HIV-positive status The impact (if any) the experience had on participants and their interaction with others in their life Participants were also asked about any harmful effects of participating in the project.
Norris & DeMarco (2005)	 Focus groups were conducted to answer the following questions: What was it like to be filmed for this project [women with HIV making a film about their life story]? Are there any positive things that you would like to share? Are there any negative things that you would like to share? Do you have any other insights?
Parsons et al. (2004)	Participants completed a 90-minute face-to-face interview. A full list of interview questions was not provided. A standardised interview guide of open-ended questions was used to explore: • Experiences of drug use • Sexuality and sexual experiences over the previous three months • HIV-related experiences • Access to healthcare and treatment adherence • Mental health • Disclosure of HIV-positive serostatus • Detailed narratives about recent sexual encounters deemed low risk versus unsafe
Paxton (2002)	In-depth interviews were conducted according to the article but no further details about interview questions or content are provided.

The findings from the qualitative literature provide information about individuals' experiences of self-stigma and indicate that disclosure generally has

more positive than negative outcomes, specifically in relation to reducing shame and increasing self-acceptance or promoting a positive sense of self. These findings are explored in more detail below.

The experience of self-stigma.

Five of the eight qualitative studies explored or commented on participants' experiences of self-stigma. In these five studies, shame or internalised shame were consistently spoken about by participants. Other concepts related to self-stigma that were referred to in these studies include feelings of worthlessness or uselessness due to participants' HIV+ status, negative self-image, self-blame and guilt, and existential despair. Most of the studies referred to several of these concepts apart from one which only referred to shame (Machtinger et al., 2015).

The three studies which did not explore self-stigma directly (Frye et al., 2009; Holt et al., 1998; Parsons et al., 2004) referred to it in the context of the impact of disclosure. Two studies (Buseh & Stevens, 2007; Donnelly et al., 2016) highlighted stigma-related challenges participants faced at the social and structural levels, such as being rejected by friends and family, or feeling disrespected when accessing healthcare or other services, even when they had not voluntarily disclosed their HIV status. This prevented some participants from accessing services and led to increased withdrawal and isolation, thus preventing opportunities for positive disclosure experiences.

Positive effects of disclosure on self-stigma.

Seven of the eight qualitative studies highlighted at least some positive effects of disclosure on self-stigma or related concepts. Participants most commonly spoke about being able to overcome negative feelings they held about themselves such as shame or guilt (Buseh & Stevens, 2007; Frye et al., 2009; Holt et al., 1998; Machtinger et al., 2015; Paxton, 2002), a stronger sense of self-worth (Norris & DeMarco, 2005; Paxton, 2002), becoming more comfortable with being themselves, feeling more accepting of their HIV+ status and thereby developing a more positive

sense of identity (de Vries et al., 2016; Frye et al., 2009; Holt et al., 1998; Machtinger et al., 2015; Norris & DeMarco, 2005; Parsons et al., 2004) following disclosure.

One study also found that speaking openly about one's experiences with HIV in a peer group setting was validating and liberating even when it involved thinking about painful past experiences (Norris & DeMarco, 2005). The benefits of disclosing to peers in a support group or other peer setting were also identified by Buseh and Stevens (2007) and Frye et al. (2009). Overall the findings suggest that sharing one's experiences with others in a similar situation has a freeing and normalising effect.

Positive disclosure experiences in a peer group setting also seemed to lead to increased disclosure outside of such groups in the form of providing education to others or engaging in public advocacy, which can further decrease negative feelings about oneself (Buseh & Stevens, 2007; Frye et al., 2009; Machtinger et al., 2015), and increase self-confidence and empowerment (Paxton, 2002).

Negative effects of disclosure on self-stigma.

Three studies found that disclosure can have negative effects. For some people, the effect of disclosure on self-stigma depended on the reaction from the person or people to whom the disclosure was made (Donnelly et al., 2016).

Negative reactions such as rejection reinforced the individual's existing negative perceptions of themselves, thereby increasing self-stigma (Donnelly et al., 2016; Holt et al., 1998). An example given in one study concerned a participant who had disclosed their HIV-positive status to a friend who then started avoiding the participant, leaving them feeling useless and afraid of rejection (Donnelly et al., 2016).

Negative reactions and discrimination from service providers increased feelings of shame and created a barrier to accessing services (Donnelly et al., 2016). Negative experiences such as service refusal and breaches of confidentiality

occurred in clinics that were not HIV specialists (e.g. general hospitals, dentists), whereas HIV-specialist providers were described as providing more comfortable and safer spaces (Donnelly et al., 2016). The experience of being marginalised and excluded was particularly strong for participants having to manage multiple layers of stigma relating to other parts of their identity such as their ethnicity or sexuality (Donnelly et al., 2016).

One study highlighted 'timing' as a contextual factor which contributed to negative disclosure outcomes for several participants in the context of disclosing to their primary partner and could lead to disclosure having a negative impact on self-perception (Parsons et al., 2004). One participant described how they disclosed their HIV status to their partner after having unprotected sex with them, and the resulting distress for both of them left the participant feeling "like a piece of shit" (Parsons et al., 2004, p.466).

Findings from quantitative studies.

Two studies used correlations to analyse the data (de Vries et al., 2016; Emlet, 2006). One study used one-way ANOVAs to compare mean self-stigma scores between different groups (Geary et al., 2014). Two studies conducted correlational and regression analyses (Heggeness et al., 2017; Lyimo et al., 2014). Two studies conducted linear regressions (Li et al., 2016; Swendeman et al., 2006), and one study used both correlations and mediation/moderation analyses (Prati et al., 2016). Table 3 contains a summary of the type of analyses conducted in each study and the main findings relevant to this review.

The relationship between disclosure and self-stigma.

Five of the seven quantitative studies and the mixed method study reported a significant relationship between disclosure of HIV-positive status and self-stigma (de Vries et al., 2016; Geary et al., 2014; Heggeness et al., 2017; Lyimo et al., 2014; Prati et al., 2016; Swendeman et al., 2006). Three studies indicated that higher levels of disclosure were associated with lower levels of self-stigma and shame

(Heggeness et al., 2017; Prati et al., 2016; Swendeman et al., 2006), one study highlighted an association with feeling stronger (de Vries et al., 2016), and one study reported that voluntary disclosure significantly predicted self-stigma when controlling for potential confounders (Lyimo et al., 2014). People who disclosed to their spouse or partner and those who belonged to a support group (which is likely to involve disclosure) had significantly lower self-stigma scores than those who did not (Geary et al., 2014). Two studies found no significant relationship between HIV status disclosure and self-stigma or negative self-image (Emlet, 2006; Li et al., 2016).

Demographic variables.

Findings showed no significant differences in self-stigma scores between younger and older adults (Emlet, 2006), with both groups reporting high levels of shame about their HIV-positive status, or between genders (Geary et al., 2014). Disclosure rates were higher among men (Geary et al., 2014), although most studies included in this review did not assess this. Disclosure was linked to better engagement in HIV care (Prati et al., 2016), and for women only was associated with improved perceptions of their own health (Geary et al., 2014). Finally, one study showed that marital status can affect the likelihood of disclosure to one's spouse or partner, with 65.6% of married participants disclosing to their spouse as opposed to 9% of those with a partner (Lyimo et al., 2014). However, this study took place in Tanzania where homosexuality is criminalised and same-sex couples have no legal recognition (Carroll & Mendos, 2017), and the study did not report data on participants' sexual orientation, thereby limiting the generalisability of the findings to more diverse samples in countries which do not persecute LGBTQ+ people. As marriage is not an option for LGBTQ+ people in this and many other countries (Carroll & Mendos, 2017), the association between marital status and likelihood of disclosure should be considered cautiously.

Discussion

This review presents the main findings of studies looking at the relationship between disclosure and self-stigma in people living with HIV with a specific focus on the impact of disclosure on self-stigma, and has appraised the quality of these studies. A summary of the key findings and themes is presented below in the relation to the research question addressed by this review, followed by a discussion of the limitations, implications and suggestions for future research.

The effect of disclosure on self-stigma in people living with HIV

The research question this review aimed to address was: How does disclosure of a concealable stigmatised identity affect self-stigma or sense of self in people who are HIV-positive? The majority of findings from the quantitative literature established a significant relationship between disclosure and self-stigma in this population. Several studies reported that higher levels of disclosure were associated with lower levels of shame and self-stigma, and there was some evidence for an association between higher levels of disclosure and feeling more resilient. However, two of the quantitative studies found no relationship between disclosure and self-stigma. There were no marked differences in the quality ratings of the quantitative studies which did and those which did not find a relationship between disclosure and self-stigma, as they all fell within the 'fair' category.

Whilst the cross-sectional nature of the quantitative studies limited inferences about causality, the qualitative studies highlighted that people who disclosed developed a more positive self-perception as a result of this, including a reduced sense of shame, increased self-worth and self-acceptance, and an ability to integrate their HIV-positive status into their sense of identity in a more positive way than prior to disclosure. However, some contexts appeared more favourable to positive disclosure experiences than others. Peer support settings appeared particularly validating and normalising settings for disclosure (Buseh & Stevens,

2007; Frye et al., 2009; Norris & DeMarco, 2005), which could help HIV+ individuals develop the confidence for increased disclosure outside of peer settings, and allowed some to become educators and advocates. Increased confidence and improved self-perception seem to occur alongside other positive effects of peer support group participation. These include increased emotional and social support, reduced felt stigma and discrimination, increased acceptance of their HIV diagnosis and hope for the future, and improvements, increased care seeking and reductions in anxiety and insomnia (Bateganya, Amanyeiwe, Roxo & Dong, 2015), as well as a sense of agency over their treatment due to improved understanding of the illness and benefits of antiretroviral medication (Chime, Arinze-Onyia & Obionu, 2018). It is not possible to conclude from the findings of the studies included in this review to what extent these other factors mediate the effect of disclosure on self-stigma.

On the other hand, there was some evidence that healthcare and other service providers which are not specialist HIV services can be negative disclosure recipients, as some participants described experiences of discrimination and disrespectful treatment due to their HIV-positive status (Donnelly et al., 2016).

Negative reactions from other people seemed to be the main contributing factor in situations where disclosure had a negative impact upon self-stigma and reinforced people's negative view of themselves. The impact of negative disclosure experiences was compounded for people who experienced stigma and discrimination due to other characteristics such as ethnicity or sexuality in addition to their HIV-positive status.

The findings around positive and negative effects of disclosure on selfstigma seemed to complement rather than contradict each other in terms of the effects being context-dependent. Whilst the two studies which scored as 'poor' in the quality ratings both reported only positive effects of disclosure on self-stigma or sense of self, the other four studies which also found only positive effects of disclosure on self-stigma and the three studies which found negative (or both negative and positive) effects were all methodologically sounder. It can therefore not be argued that the findings on either side should be given more weight or credibility.

The findings fit with theoretical frameworks such as the Disclosure Processes Model (Chaudoir & Fisher, 2010) which proposes that the motivations and goals (approach versus avoidance goals) of the disclosing person as well as the reaction of the disclosure target are important factors affecting the outcome of a disclosure. The adaptation of this model for HIV disclosure (Chaudoir et al., 2011) takes into account other antecedent factors such as the serostatus of the disclosure target. The model also accounts for the positive experience of those who disclosed with the goal of gaining support and understanding in a safe peer group setting with other HIV-positive people, or to educate and become a role model to others.

The findings are also in line with previous research which found that in some instances people living with HIV are treated particularly badly by healthcare providers outside specialist HIV care settings, for example by being refused care, being given poorer care than HIV-negative patients, and being treated disrespectfully (e.g. with unnecessary distance and excessive precautions; being whispered about by staff) (Karamouzian et al., 2015). This might be linked to factors such as HIV knowledge and training, perceived institutional support, level of education, religious affiliation, race and type of clinic setting (Feyissa, Abebe, Girma, & Woldie, 2012; Stringer et al., 2016). Poor treatment, stigma and discrimination in healthcare settings has been identified as a barrier to people living with HIV accessing healthcare (Kinsler, Wong, Sayles, Davis & Cunningham, 2007), and it is also linked to increased shame and self-isolation (Zukoski & Thorburn, 2009) which further contribute to care seeking and negatively affect an individual's mental health (Simbayi et al., 2007). Particularly marginalised groups, such as men who have sex with men or people who use drugs, have reported experiences multiple layers of stigma and discrimination which further increase the likelihood of negative health outcomes (Duby, Nkosi, Scheibe, Brown & Bekker, 2018).

Generalisability or transferability of the findings.

The quality appraisal scores for the criterion of 'transferability or generalisability' were variable, with two studies rated good, ten as fair, and four as poor. Some studies were rated fair due to the adequate transferability of their findings to people living with HIV who shared similar characteristics rather than their generalisability to a wider population, the latter being limited by the sampling techniques and/or criteria employed by the studies (e.g. Buseh & Stevens, 2007; Parsons et al., 2004). Lower 'transferability and generalisability' scores were often linked to lower 'sampling' scores because more biased or specific sampling strategies (e.g. sampling a very specific sub-group of HIV-positive people) or insufficient descriptions of the sampling strategy limited the transferability and generalisability of the findings.

In addition, as most of the studies included in this review were conducted in Western countries, especially the subset of qualitative studies (which were the ones that established an effect of disclosure on self-stigma), generalisability is limited to countries or regions with similar attitudes, beliefs and norms. Similarly, generalisability might be limited as a result of changes in social attitudes to people living with HIV over time. Half the studies included in this review were published fairly recently, within the past four years, whereas the other half were published between 10 and 20 years ago. However, people living with HIV may continue to be affected by perceived stigma and stigma related to interpersonal closeness at the same level as 15 years ago. (Visser, 2018).

There are some parallels between the findings of this review and findings of research studies involving groups of people with other concealable stigmatised identities which could be seen as support the findings of this review. For example, some people report that receiving a positive response to their disclosure of mental health problems helped them feel 'stronger' and that being an educator or role

model to others instilled in them a sense of purpose (Bril-Barniv et al., 2017), whilst the experience of sharing positive, empowering stories with peers can help to overcome feelings of shame about mental health difficulties (Buchholz, Aylward, McKenzie, & Corrigan, 2015). Similarly, gay men who disclosed their sexual orientation to a group of other men of mixed sexual orientations and received a positive response reported that this felt validating and affirming, and helped to reduce their sense of shame about their sexual orientation (Provence et al., 2014).

On the other hand, negative reactions and judgments from others following disclosure of a mental health problem can lead to an increase in shame and distress (Pyle & Morrison, 2014), and negative responses from family members to an individual's disclosure of their sexual orientation have been associated with decreased self-esteem (Ryan, Legate, & Weinstein, 2015) and poorer mental health outcomes (Rothman, Sullivan, Keyes, & Boehmer, 2012). This is congruent with the findings of this review, in that disclosure may decrease shame and self-stigma in supportive settings but not when others respond negatively to finding out about the concealable stigmatised identity.

However, societal perceptions of different stigmatised attributes are likely to affect the generalisability of the findings, in that HIV-positive status may carry more or less societal stigma than other attributes such as sexual orientation or illicit drug use in a given country, influenced by the country's norms, traditions, laws and awareness campaigns. In many countries across the world LGBTQ+ individuals or people with mental health problems experience high levels of stigma, discrimination and abuse (Stonewall, 2017; World Health Organisation, 2010) similar to experiences reported by people living with HIV (Dlamini et al., 2007). On the other hand, public perceptions might differ in some countries as a result of awareness campaigns. For example, one could argue that HIV awareness campaigns such as 'National HIV Testing Week' and 'It starts with me', which are part of the national HIV Prevention England programme (Terrence Higgins Trust, 2018), have a fairly

strong focus on reducing stigma around specific health outcomes such as HIV testing, whereas campaigns targeting public stigma and discrimination towards people with mental health problems (e.g. '*Time To Change'*), or LGBTQ+ individuals (e.g. Stonewall's '*Get Over It!*' campaign) address societal stigma more directly. This might lead to differences in public attitudes towards different stigmatised attributes, which could in turn affect the response of a disclosure target.

Finally, generalisability might be situation-specific as there may be some situations where stigma is more specific to HIV-positive people (e.g. disclosure to [potential] sexual partners) and others where people with a range of concealable stigmatised identities are more likely to encounter similar reactions (e.g. disclosure to a supportive loved one).

Limitations of this review

This review has several limitations to be noted. Firstly, it was beyond the scope of this review to include all terms of relevance to self-stigma. For example, 'low self-esteem' could be seen as a process accompanying self-stigma but the term self-esteem was excluded from the final searches as initial scoping searches with this term returned too many results that were not relevant to this topic. As a result, it is possible that some articles eligible for inclusion in this review may have been missed in the searches.

Similarly, inconsistencies in the outcome measures and terminology used to describe self-stigma affected the study selection process. For example, Swendeman et al. (2006) used the term 'perceived stigma' to encompass concepts relating to self-stigma such as internalised shame. Studies were included where it could be verified that their measure of stigma included items measuring self-stigma or related concepts, and that the relationship between these items and disclosure was separately assessed (rather than just being included in an overall stigma score). However, it is possible that some relevant studies were not identified in the

database searches or selected in the screening process as a result of limited clarity around what they were measuring.

A third limitation concerns the difficulty of systematically applying the inclusion criteria related to 'outcomes'. Specifically, the sub-criterion stating that the relationship between disclosure and self-stigma had to be a clear theme or main outcome of the study was somewhat subjective and difficult to define. This difficulty mainly arose in studies which looked at several different themes or outcomes in their results section so that each outcome or theme only received fairly brief mention. In qualitative studies this would often mean having only one to three quotes to evidence a relevant theme. Qualitative studies were included where the relationship between disclosure and self-stigma received a similar amount of attention as other themes or sub-themes within the relevant section. Quantitative studies were included if the results pertaining to the relationship between disclosure and self-stigma were referred to in text, even if this was brief, rather than just presented in a table. However, the subjective nature of this criterion could affect the replicability of this review as other researchers might decide to include or exclude studies that were rated differently to this review.

It should be noted that there is a possibility of the researchers being influenced during the study selection and data extraction process by their pre-existing interest in disclosure and its positive effects. Whilst the intention was to look at the literature in an objective and balanced way the possibility of bias has to be acknowledged.

Another key limitation is that all the quantitative studies were cross-sectional thereby limiting the conclusions that can be drawn about the impact of disclosure on self-stigma, as the direction of the effect is unclear. In addition, although there was some geographic variability across the studies included in this review, the majority were conducted in Western societies. Therefore, it is not possible to conclude whether disclosure would lead to similar outcomes in countries and cultures with

different approaches to healthcare, cultural values and norms, and perceptions of HIV-positive people. Further, only studies written in English language were included and therefore any findings from study reported in other languages which may have supported or contradicted the conclusions drawn in this review have not been taken into consideration.

Finally, the qualitative studies provided far richer information than could be portrayed in this review. Whilst an attempt was made to extract the key findings and mutual themes, some of the relevant details available in the original studies will inevitably have been lost.

Policy or practice implications

The findings summarised in this review indicate that, in supportive contexts, disclosure can improve an individual's self-perception and reduce self-stigma and shame. As shame and self-stigma are predictors of mental and physical health outcomes such as anxiety and depression (Murphy, Garrido-Hernansaiz, Mulcahy & Hevey, 2018) and engagement in and adherence to medical care (Earnshaw et al., 2013), reducing these can have a positive effect on clinical outcomes. As peer support groups appear to be one of the settings experiences as helpful and validating for disclosure, offering more peer support in schools, universities, workplaces and healthcare settings may help people access the support they need and help facilitate positive disclosure experiences which could have a positive impact upon their sense of self.

The findings also indicated that healthcare professionals in some non-specialist services may be perceived as acting in stigmatising or discriminatory ways towards people living with HIV, possibly due to limited training and awareness of HIV. Specialist HIV clinics and organisations could be a useful learning resource to identify ways to create a comfortable and safe environment that facilitates disclosure. HIV stigma reduction interventions appear to be more effective when aimed at professional audiences and when they occur over multiple sessions rather

than as one-offs (Mak, Mo, Ma, & Lam, 2017) which should be taken into account when designing interventions. Contact interventions with HIV-positive educators who deliver or co-deliver training sessions would be one way of delivering such interventions, as intergroup contact has been identified as an effective way of reducing prejudice (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012; Pettigrew & Tropp, 2006), although the impact of contact with HIV-positive people in HIV-specific stigma interventions is less clear (Mak et al., 2017).

Directions for future research

This review identified some of the settings and factors that made it more likely for disclosure to have a positive impact on self-stigma. It could be beneficial for future research to look more closely at the factors and contexts associated with positive and negative outcomes to better inform those providing support services, advice and interventions to HIV-positive people. Similarly, it would be helpful for future research to explore the effects of disclosure on self-stigma in a wider range of countries and cultures, to better understand whether or not outcomes and influencing factors are comparable across different countries.

In addition, it would be useful for future research to include prospective cohort studies as this would allow researchers to measure shame and self-stigma prior to disclosure in those who are diagnosed as HIV positive, and to measure how self-stigma is affected over time in those who choose to disclose and those who choose not to disclose, thereby providing a clearer picture of the relationship between disclosure and self-stigma.

Several of the quantitative studies included in this review asked participants to report whether they had disclosed to different types of people (e.g. family, friends, colleagues, healthcare professionals) but then did not report data on the associations between disclosure to different types of individuals and self-stigma. It might be useful to investigate whether disclosure to certain types of individuals has a stronger effect on self-stigma than to others. This could, for example, inform

decisions around which groups to target with awareness and educational campaigns or clinical interventions. Also, if disclosure to a specific type of disclosure target seems to result in particularly positive outcomes, future research could focus on identifying the factors that differentiate that disclosure target group to further inform self-stigma interventions.

Finally, this field would benefit from more consistent use of terminology and outcome measures. The studies reviewed used diverse methods to measure self-stigma which made it more difficult to compare results and ascertain that they were measuring the same concept. A clearer definition of the different components of stigma (including self-stigma), which takes into account variations in cultural norms and beliefs pertaining to this concept, as well as a primary outcome measure that has been internationally validated or adapted where necessary, would benefit empirical research in this field.

References

- Avert. (2018). History of HIV and AIDS overview. Retrieved December 3, 2018, from https://www.avert.org/professionals/history-hiv-aids/overview
- Bateganya, M. H., Amanyeiwe, U., Roxo, U., & Dong, M. (2015). The Impact of Support Groups for People Living with HIV on Clinical Outcomes: a systematic review of the literature. *Journal of acquired immune deficiency syndromes*, 68(Suppl. 3), S368-S374.

 https://doi.org/10.1097/QAI.000000000000519
- Berger, B. E., Ferrans, C. E., & Lashley, F. R. (2001). Measuring stigma in people with HIV: Psychometric assessment of the HIV stigma scale. *Research in Nursing and Health*, *24*, 518–529. https://doi.org/10.1002/nur.10011
- Bril-Barniv, S., Moran, G. S., Naaman, A., Roe, D., & Karnieli-Miller, O. (2017). A

 Qualitative Study Examining Experiences and Dilemmas in Concealment and

 Disclosure of People Living with Serious Mental Illness. *Qualitative Health*Research, 27, 573–583. https://doi.org/10.1177/1049732316673581
- Brohan, E., Henderson, C., Wheat, K., Malcolm, E., Clement, S., Barley, E. A., ...

 Thornicroft, G. (2012). Systematic review of beliefs, behaviours and influencing factors associated with disclosure of a mental health problem in the workplace. *BMC Psychiatry*, 12. https://doi.org/10.1186/1471-244X-12-11
- Buchholz, B., Aylward, S., McKenzie, S., & Corrigan, P. (2015). Should youth disclose their mental health challenges? Perspectives from students, parents, and school professionals. *Journal of Public Mental Health*, *14*, 159–168. https://doi.org/10.1108/JPMH-03-2015-0008
- Bunn, J. Y., Solomon, S. E., Miller, C., & Forehand, R. (2007). Measurement of Stigma in People with HIV: A Reexamination of the HIV Stigma Scale. AIDS Education and Prevention, 19, 198–208. https://doi.org/10.1521/aeap.2007.19.3.198

- Buseh, A. G., & Stevens, P. E. (2007). Constrained But Not Determined by Stigma:

 Resistance by African American Women Living with HIV. Women & Health,

 44, 1–18. https://doi.org/10.1300/J013v44n03_01
- Carroll, A., & Mendos, L. R. (2017). State-Sponsored Homophobia 2017: A world survey of sexual orientation laws: criminalisation, protection and recognition.

 Geneva, Switzerland: International Lesbian, Gay, Bisexual, Trans and Intersex Association. Retrieved from https://ilga.org/state-sponsored-homophobia-report
- Chaudoir, S. R., & Fisher, J. D. (2010). The disclsoure process model:

 Understanding disclosure decision-making and post-disclosure outcomes among people living with a concealable stigmatized identity. *Psychological Bulletin*, 136, 236–256. https://doi.org/10.1037/a0018193.
- Chaudoir, S. R., Fisher, J. D., & Simoni, J. M. (2011). Understanding HIV disclosure:

 A review and application of the Disclosure Processes Model. *Social Science*& *Medicine*, 72, 1618–1629. https://doi.org/10.1016/j.socscimed.2011.03.028
- Chime, O. H., Arinze-Onyia, S. U., & Obionu, C. N. (2018). Do peer support groups have an effect on medication adherence? A study among people living with HIV/AIDS in Enugu State, Nigeria. *Proceedings of Singapore Healthcare, 27*, 256–264. https://doi.org/10.1177/2010105818760923
- Corrigan, P. W., Kosyluk, K. A., & Rüsch, N. (2013). Reducing self-stigma by coming out proud. *American Journal of Public Health*, *103*, 794–800. https://doi.org/10.2105/AJPH.2012.301037
- Corrigan, P. W., Larson, J. E., Hautamaki, J., Matthews, A., Kuwabara, S., Rafacz, J., ... O'Shaughnessy, J. (2009). What lessons do coming out as gay men or lesbians have for people stigmatized by mental illness? *Community Mental Health Journal*, *45*, 366–374. https://doi.org/10.1007/s10597-009-9187-6

- Corrigan, P. W., Larson, J. E., Michaels, P. J., Buchholz, B. A., Rossi, R. Del, Fontecchio, M. J., ... Rüsch, N. (2015). Diminishing the self-stigma of mental illness by coming out proud. *Psychiatry Research*, 229, 148–154. https://doi.org/10.1016/j.psychres.2015.07.053
- Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsch, N. (2012).

 Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome Studies. *Psychiatric Services*, *63*, 963–973.

 https://doi.org/10.1176/appi.ps.201100529
- Corrigan, P. W., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P., ...

 Rüsch, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology*, *38*, 259–275.

 https://doi.org/10.1002/jcop.20363
- Corrigan, P. W., & Rao, D. (2012). On the self-stigma of mental illness: Stages, disclosure, and strategies for change. *Canadian Journal of Psychiatry*, *57*, 464–469. https://doi.org/10.1177/070674371205700804
- D'Augelli, A. R., & Grossman, A. H. (2001). Disclosure of Sexual Orientation,

 Victimization, and Mental Health Among Lesbian, Gay, and Bisexual Older

 Adults. *Journal of Interpersonal Violence*, *16*, 1008–1027.

 https://doi.org/10.1177/088626001016010003
- de Vries, D. H., Koppen, L., Lopez, A. M., & Foppen, R. (2016). The vicious cycle of stigma and disclosure in "Self-management": A study among the Dutch HIV population. *AIDS Education and Prevention*, *28*, 485–498. https://doi.org/10.1521/aeap.2016.28.6.485
- Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness. *British Journal of Psychiatry*, *184*, 176–181. https://doi.org/10.1192/bjp.184.2.176

- Dlamini, P. S., Kohi, T. W., Uys, L. R., Phetlhu, R. D., Chirwa, M. L., Naidoo, J. R., ... Makoae, L. N. (2007). Verbal and Physical Abuse and Neglect as Manifestations of HIV/AIDS Stigma in Five African Countries. *Public Health Nursing*, 24, 389–399. https://doi.org/10.1111/j.1525-1446.2007.00649.x
- Donnelly, L. R., Bailey, L., Jessani, A., Postnikoff, J., Kerston, P., & Brondani, M. (2016). Stigma Experiences in Marginalized People Living With HIV Seeking Health Services and Resources in Canada. *Journal of the Association of Nurses in AIDS Care*, 27, 768–783. https://doi.org/10.1016/j.jana.2016.07.003
- Duby, Z., Nkosi, B., Scheibe, A., Brown, B., & Bekker, L. (2018). 'Scared of going to the clinic': Contextualising healthcare access for men who have sex with men, female sex workers and people who use drugs in two South African cities. Southern African Journal of HIV Medicine, 19, 701-708. https://doi.org/10.4102/sajhivmed.v19i1.701
- Earnshaw, V. A., Smith, L. R., Chaudoir, S. R., Amico, K. R., & Copenhaver, M. M. (2013). HIV stigma mechanisms and well-being among PLWH: a test of the HIV stigma framework. *AIDS and Behavior*, *17*, 1785–1795. https://doi.org/10.1007/s10461-013-0437-9
- Emlet, C. A. (2006). A Comparison of HIV Stigma and Disclosure Patterns Between Older and Younger Adults Living with HIV/AIDS. *AIDS Patient Care and STDs*, *20*, 350–358. https://doi.org/10.1089/apc.2006.20.350
- Feyissa, G. T., Abebe, L., Girma, E., & Woldie, M. (2012). Stigma and discrimination against people living with HIV by healthcare providers, Southwest Ethiopia.

 **BMC Public Health*, 12, 522. https://doi.org/http://dx.doi.org/10.1186/1471-2458-12-522

- Frye, V., Fortin, P., MacKenzie, S., Purcell, D., Edwards, L. V., Mitchell, S. G., ...

 Latka, M. H. (2009). Managing identity impacts associated with disclosure of

 HIV status: A qualitative investigation. *AIDS Care*, *21*, 1071–1078.

 https://doi.org/10.1080/09540120802657514
- Geary, C., Parker, W., Rogers, S., Haney, E., Njihia, C., Haile, A., & Walakira, E. (2014). Gender differences in HIV disclosure, stigma, and perceptions of health. *AIDS Care*, 26, 1419–1425. https://doi.org/10.1080/09540121.2014.921278
- Goffman, E. (1963). Stigma: Notes on the Management of Spoiled Identity. New York, NY: Simon and Schuster.
- Grice, T., Alcock, K., & Scior, K. (2018). Factors Associated With Mental Health Disclosure Outside of the Workplace: A Systematic Literature Review. Stigma and Health, 3, 116-130. https://doi.org/10.1037/sah0000079
- Hawker, S., Payne, S., Kerr, C., Hardey, M., & Powell, J. (2002). Appraising the Evidence: Reviewing Disparate Data Systematically. *Qualitative Health* Research, 12, 1284–1299. https://doi.org/10.1177/1049732302238251
- Heggeness, L. F., Brandt, C. P., Paulus, D. J., Lemaire, C., & Zvolensky, M. J. (2017). Stigma and disease disclosure among HIV+ individuals: the moderating role of emotion dysregulation. *AIDS Care*, 29, 168–176. https://doi.org/10.1080/09540121.2016.1204419
- Holt, R., Court, P., Vedhara, K., Nott, K. H., Holmes, J., & Snow, M. H. (1998). The role of disclosure in coping with HIV infection. *AIDS Care*, *10*, 49–60. https://doi.org/10.1080/09540129850124578
- Jones, M., & Williams, M. L. (2015). Twenty years on: lesbian, gay and bisexual police officers' experiences of workplace discrimination in England and Wales. *Policing and Society*, *25*, 188–211. https://doi.org/10.1080/10439463.2013.817998

- Kalichman, S. C., Simbayi, L. C., Cloete, A., Mthembu, P. P., Mkhonta, R. N., & Ginindza, T. (2009). Measuring AIDS stigmas in people living with HIV/AIDS: the Internalized AIDS-Related Stigma Scale. AIDS Care, 21, 87–93. https://doi.org/10.1080/09540120802032627
- Karamouzian, M., Akbari, M., Haghdoost, A. A., Setayesh, H., & Zolala, F. (2015). "I Am Dead to Them": HIV-related Stigma Experienced by People Living With HIV in Kerman, Iran. *Journal of the Association of Nurses in AIDS Care*, 26, 46–56. https://doi.org/10.1016/j.jana.2014.04.005
- Kinsler, J. J., Wong, M. D., Sayles, J. N., Davis, C., & Cunningham, W. E. (2007).

 The Effect of Perceived Stigma from a Health Care Provider on Access to

 Care Among a Low-Income HIV-Positive Population. *AIDS Patient Care and*STDs, 21, 584-592. https://doi.org/10.1089/apc.2006.0202
- Lam, P. K., Naar-King, S., & Wright, K. (2007). Social Support and Disclosure as Predictors of Mental Health in HIV-Positive Youth. *AIDS Patient Care and STDs*, *21*, 20–29. https://doi.org/10.1089/apc.2006.005
- Lee, R. S., Kochman, A., & Sikkema, K. J. (2002). Internalized stigma among people living with HIV-AIDS. *AIDS and Behavior*, *6*, 309–319. https://doi.org/10.1023/A:1021144511957
- Li, Z., Hsieh, E., Morano, J. P., & Sheng, Y. (2016). Exploring HIV-related stigma among HIV-infected men who have sex with men in Beijing, China: a correlation study. *AIDS Care*, *28*, 1394–1401. https://doi.org/10.1080/09540121.2016.1179713
- Lyimo, R. A., Stutterheim, S. E., Hospers, H. J., de Glee, T., van der Ven, A., & de Bruin, M. (2014). Stigma, Disclosure, Coping, and Medication Adherence Among People Living with HIV/AIDS in Northern Tanzania. *AIDS Patient Care and STDs*, 28, 98–105. https://doi.org/10.1089/apc.2013.0306

- Machtinger, E. L., Lavin, S. M., Hilliard, S., Jones, R., Haberer, J. E., Capito, K., & Dawson-Rose, C. (2015). An Expressive Therapy Group Disclosure
 Intervention for Women Living With HIV Improves Social Support, Selfefficacy, and the Safety and Quality of Relationships: A Qualitative Analysis.
 Journal of the Association of Nurses in AIDS Care, 26, 187–198.
 https://doi.org/10.1016/j.jana.2014.05.001
- Mak, W. W. S., Cheung, R. Y. M., Law, R. W., Woo, J., Li, P. C. K., & Chung, R. W. Y. (2007). Examining attribution model of self-stigma on social support and psychological well-being among people with HIV+/AIDS. Social Science & Medicine, 64, 1549–1559. https://doi.org/10.1016/j.socscimed.2006.12.003
- Mak, W. W. S., Mo, P. K. H., Ma, G. Y. K., & Lam, M. Y. Y. (2017). Meta-analysis and systematic review of studies on the effectiveness of HIV stigma reduction programs. *Social Science & Medicine*, *188*, 30–40. https://doi.org/10.1016/j.socscimed.2017.06.045
- Meacham, E., Orem, J., Nakigudde, G., Zujewski, J. A., & Rao, D. (2016). Exploring stigma as a barrier to cancer service engagement with breast cancer survivors in Kampala, Uganda. *Psycho-Oncology*, *25*, 1206–1211. https://doi.org/10.1002/pon.4215
- Moyer, E., Igonya, E. K., Both, R., Cherutich, P., & Hardon, A. (2013). The duty to disclose in Kenyan health facilities: A qualitative investigation of HIV disclosure in everyday practice. *SAHARA-J: Journal of Social Aspects of HIV/AIDS*, *10*, S60–S72. https://doi.org/10.1080/02664763.2012.755339
- Mulfinger, N., Müller, S., Böge, I., Sakar, V., Corrigan, P. W., Evans-Lacko, S., ...

 Rüsch, N. (2018). Honest, Open, Proud for adolescents with mental illness:

 pilot randomized controlled trial. *Journal of Child Psychology and Psychiatry*,

 59, 684–691. https://doi.org/10.1111/jcpp.12853

- Murphy, P. J., Garrido-Hernansaiz, H., Mulcahy, F. & Hevey, D. (2018). HIV-related stigma and optimism as predictors of anxiety and depression among HIV-positive men who have sex with men in the United Kingdom and Ireland.

 AIDS Care, 30, 1173-1179.
- Norris, A. E., & DeMarco, R. (2005). The experience of African American women living with HIV: Creating a prevention film for teens. *Journal of the Association of Nurses in AIDS Care*, *16*, 32–39. https://doi.org/10.1016/j.jana.2005.01.002
- Overstreet, N. M., Earnshaw, V. A., Kalichman, S. C., & Quinn, D. M. (2013).

 Internalized stigma and HIV status disclosure among HIV-positive black men who have sex with men. *AIDS Care*, *25*, 466–471.

 https://doi.org/10.1080/09540121.2012.720362
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, *133*, 328–345. https://doi.org/10.1037/0033-2909.133.2.328
- Paré, G., & Kitsiou, S. (2016). Methods for Literature Reviews. In F. Lau & C.
 Kuziemsky (Eds.), Handbook of eHealth Evaluation: An Evidence-based
 Approach (pp. 157-179). Victoria, British Columbia, Canada: University of Victoria.
- Parsons, J. T., VanOra, J., Missildine, W., Purcell, D. W., & Gomez, C. A. (2004).
 Positive and negative consequences of HIV disclosure among seropositive injection drug users. AIDS Education and Prevention, 16, 459–475.
 https://doi.org/10.1521/aeap.16.5.459.48741
- Paxton, S. (2002). The paradox of public HIV disclosure. *AIDS Care*, *14*, 559–567. https://doi.org/10.1080/09540120220133080
- Pettigrew, T. F., & Tropp, L. R. (2006). A meta-analytic test of intergroup contact theory. *Journal of Personality and Social Psychology*, *90*, 751–783. https://doi.org/10.1037/0022-3514.90.5.751

- Prati, G., Zani, B., Pietrantoni, L., Scudiero, D., Perone, P., Cosmaro, L., ... Oldrini, M. (2016). The role of knowing someone living with HIV/AIDS and HIV disclosure in the HIV stigma framework: a Bayesian mediation analysis.
 Quality and Quantity, 50, 637–651. https://doi.org/10.1007/s11135-015-0168-2
- Provence, M. M., Rochlen, A. B., Chester, M. R., Smith, E. R., Provence, M. M., Rochlen, A. B., ... Smith, E. R. (2014). "Just One of the Guys ": A Qualitative Study of Gay Men's Experiences in Mixed Sexual Orientation Men's Groups.

 Psychology of Men and Masculinity, 15, 427–436.

 https://doi.org/10.1037/a0035026
- Pyle, M., & Morrison, A. P. (2014). "It's just a very taboo and secretive kind of thing":

 Making sense of living with stigma and discrimination from accounts of
 people with psychosis. *Psychosis*, *6*, 195–205.

 https://doi.org/10.1080/17522439.2013.834458
- Quinn, D. M., & Earnshaw, V. A. (2013). Concealable Stigmatized Identities and Psychological Well-Being. Social and Personality Psychology Compass, 7, 40–51. https://doi.org/10.1111/spc3.12005
- Rael, C. T., Carballo-Diéguez, A., Norton, R., Thorley, E., Giguere, R., Sheinfil, A., & Rios, J. L. (2017). Identifying Strategies to Cope with HIV-Related Stigma in a Group of Women Living with HIV/AIDS in the Dominican Republic: A Qualitative Study. AIDS and Behavior, 21, 2589–2599.
 https://doi.org/10.1007/s10461-016-1654-9
- Rael, C. T., & Davis, A. (2017). Depression and key associated factors in female sex workers and women living with HIV/AIDS in the Dominican Republic. *International Journal of STD & AIDS*, 28, 433–440. https://doi.org/10.1177/0956462416651374

- Ragins, B. R., Singh, R., & Cornwell, J. M. (2007). Making the Invisible Visible: Fear and Disclosure of Sexual Orientation at Work. *Journal of Applied Psychology*, 92, 1103–1118. https://doi.org/10.1037/0021-9010.92.4.1103
- Rothman, E. F., Sullivan, M., Keyes, S., & Boehmer, U. (2012). Parents' Supportive Reactions to Sexual Orientation Disclosure Associated With Better Health:

 Results From a Population-Based Survey of LGB Adults in Massachusetts. *Journal of Homosexuality*, *59*, 186–200.

 https://doi.org/10.1080/00918369.2012.648878
- Rüsch, N., Abbruzzese, E., Hagedorn, E., Hartenhauer, D., Kaufmann, I., Curschellas, J., ... Corrigan, P. W. (2014). Efficacy of coming out proud to reduce stigma's impact among people with mental illness: Pilot randomised controlled trial. *British Journal of Psychiatry*, 204, 391–397. https://doi.org/10.1192/bjp.bp.113.135772
- Rüsch, N., Corrigan, P. W., Todd, A. R., & Bodenhausen, G. V. (2010). Implicit self-stigma in people with mental illness. *Journal of Nervous and Mental Disease*, 198, 150–153. https://doi.org/10.1097/NMD.0b013e3181cc43b5
- Rüsch, N., Hölzer, A., Hermann, C., Schramm, E., Jacob, G. A., Bohus, M., ...

 Corrigan, P. W. (2006). Self-stigma in women with borderline personality disorder and women with social phobia. *Journal of Nervous and Mental Disease*, 194, 766–773.

 https://doi.org/10.1097/01.nmd.0000239898.48701.dc
- Ryan, W. S., Legate, N., & Weinstein, N. (2015). Coming Out as Lesbian, Gay, or Bisexual: The Lasting Impact of Initial Disclosure Experiences. *Self and Identity*, *14*, 549–569. Retrieved from https://www.tandfonline.com/doi/pdf/10.1080/15298868.2015.1029516?need Access=true

- Sayles, J. N., Hays, R. D., Sarkisian, C. A., Mahajan, A. P., Spritzer, K. L., & Cunningham, W. E. (2008). Development and Psychometric Assessment of a Multidimensional Measure of Internalized HIV Stigma in a Sample of HIV-positive Adults. *AIDS and Behavior*, 12, 748–758.
 https://doi.org/10.1007/s10461-008-9375-3
- Schwartzberg, S. S. (1994). Vitality and growth in HIV-infected gay men. Social Science & Medicine, 38, 593–602. https://doi.org/10.1016/0277-9536(94)90256-9
- Simbayi, L. C., Kalichman, S., Strebel, A., Cloete, A., Henda, N., & Mqeketo, A.
 (2007). Internalized stigma, discrimination, and depression among men and women living with HIV/AIDS in Cape Town, South Africa. Social Science & Medicine, 64, 1823–1831.
 https://doi.org/10.1016/J.SOCSCIMED.2007.01.006
- Smith, R. A., Zhu, X., & Fink, E. L. (2017). Understanding the Effects of Stigma

 Messages: Danger Appraisal and Message Judgments. *Health Communication*. Advance online publication.

 https://doi.org/10.1080/10410236.2017.1405487
- Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care*, *20*, 1266–1275. https://doi.org/10.1080/09540120801926977
- Sowell, R. L., Lowenstein, A., Moneyham, L., Demi, A., Mizuno, Y., & Seals, B. F. (1997). Resources, Stigma, and Patterns of Disclosure in Rural Women with HIV Infection. *Public Health Nursing*, *14*, 302–312. https://doi.org/10.1111/j.1525-1446.1997.tb00379.x
- Stirratt, M. J., Remien, R. H., Smith, A., Copeland, O. Q., Dolezal, C., Krieger, D., ...

 Stirratt, M. J. (2006). The Role of HIV Serostatus Disclosure in Antiretroviral

 Medication Adherence. *AIDS and Behavior*, *10*, 483–493.

 https://doi.org/10.1007/s10461-006-9106-6

- Stonewall. (2017). International work. Retrieved March 6, 2018, from http://www.stonewall.org.uk/our-work/international-work-1
- Stringer, K. L., Turan, B., McCormick, L., Durojaiye, M., Nyblade, L., Kempf, M.-C., ... Turan, J. M. (2016). HIV-Related Stigma Among Healthcare Providers in the Deep South. *AIDS and Behavior*, 20, 115–125. https://doi.org/10.1007/s10461-015-1256-y
- Stuart, H. (2006). Media Portrayal of Mental Illness and its Treatments What Effect

 Does it Have on People with Mental Illness? *CNS Drugs*, *20*, 99–106.

 https://doi.org/10.2165/00023210-200620020-00002
- Stutterheim, S. E., Bos, A. E. R., Pryor, J. B., Brands, R., Liebregts, M., & Schaalma, H. P. (2011). Psychological and Social Correlates of HIV Status Disclosure: The Significance of Stigma Visibility. *AIDS Education and Prevention*, 23, 382–392. https://doi.org/10.1521/aeap.2011.23.4.382
- Stutterheim, S. E., Bos, A. E. R., Shiripinda, I., de Bruin, M., Pryor, J. B., & Schaalma, H. P. (2012). HIV-related stigma in African and Afro-Caribbean communities in the Netherlands: Manifestations, consequences and coping.

 Psychology & Health, 27, 395–411.

 https://doi.org/10.1080/08870446.2011.585426
- Swendeman, D., Rotheram-Borus, M. J., Comulada, S., Weiss, R., & Ramos, M. E. (2006). Predictors of HIV-related stigma among young people living with HIV. Health Psychology, 25, 501–509. https://doi.org/10.1037/0278-6133.25.4.501
- Terrence Higgins Trust. (2018). National HIV Testing Week. Retrieved March 6, 2018, from https://www.hivpreventionengland.org.uk/campaigns/national-hivtesting-week/
- Thornicroft, G., Rose, D., & Kassam, A. (2007). Discrimination in health care against people with mental illness. *International Review of Psychiatry*, *19*, 113–122. https://doi.org/10.1080/09540260701278937

- Tsai, A. C., Bangsberg, D. R., Kegeles, S. M., Katz, I. T., Haberer, J. E., Muzoora, C., ... Weiser, S. D. (2013). Internalized Stigma, Social Distance, and Disclosure of HIV Seropositivity in Rural Uganda. *Annals of Behavioral Medicine*, 46, 285–294. https://doi.org/10.1007/s12160-013-9514-6
- UNAIDS. (2017). Confronting discrimination: Overcoming HIV-related stigma and discrimination in health- care settings and beyond. Retrieved from http://www.unaids.org/sites/default/files/media_asset/confronting-discrimination_en.pdf
- Van Der Straten, A., Vernon, K. A., Knight, K. R., Gómez, C. A., & Padian, N. S. (1998). Managing HIV among serodiscordant heterosexual couples: Serostatus, stigma and sex. *AIDS Care*, *10*, 533–548. https://doi.org/10.1080/09540129848406
- Visser, M. J., Kershaw, T., Makin, J. D., & Forsyth, B. W. C. (2008). Development of Parallel Scales to Measure HIV-Related Stigma. *AIDS and Behavior*, *12*, 759–771. https://doi.org/10.1007/s10461-008-9363-7
- Visser, M. J. (2018). Change in HIV-related stigma in South Africa between 2004 and 2016: a cross-sectional community study. *AIDS Care*, *30*, 734-738. https://doi.org/10.1080/09540121.2018.1425365
- Vogel, D. L., Bitman, R. L., Hammer, J. H., & Wade, N. G. (2013). Is stigma internalized? The longitudinal impact of public stigma on self-stigma. *Journal* of Counseling Psychology, 60, 311–316. https://doi.org/10.1037/a0031889
- Vyavaharkar, M., Moneyham, L., Corwin, S., Saunders, R., Annang, L., & Tavakoli, A. (2010). Relationships Between Stigma, Social Support, and Depression in HIV-Infected African American Women Living in the Rural Southeastern United States. *Journal of the Association of Nurses in AIDS Care*, 21, 144–152. https://doi.org/10.1016/j.jana.2009.07.008

- Weisz, B. M., Quinn, D. M., & Williams, M. K. (2015). Out and healthy: Being more "out" about a concealable stigmatized identity may boost the health benefits of social support. *Journal of Health Psychology*, 21, 2934–2943. https://doi.org/10.1177/1359105315589392
- Wohl, A. R., Galvan, F. H., Myers, H. F., Garland, W., George, S., Witt, M., ... Lee, M. L. (2011). Do Social Support, Stress, Disclosure and Stigma Influence Retention in HIV Care for Latino and African American Men Who Have Sex with Men and Women? AIDS and Behavior, 15, 1098–1110. https://doi.org/10.1007/s10461-010-9833-6
- Wong, L. H., Rooyen, H. Van, Modiba, P., Richter, L., Gray, G., Sa, F., ... Coates, T. (2009). Test and Tell: Correlates and Consequences of Testing and Disclosure of HIV Status in South Africa. *Epidemiology and Social Science*, 50, 12–14. https://doi.org/10.1097/QAI.0b013e3181900172
- World Health Organization. (2010). *Mental Health and Development: Targeting*people with mental health conditions as a vulnerable group. Retrieved from
 http://www.who.int/mental_health/policy/mhtargeting/en/
- Zukoski, A. P., & Thorburn, S. (2009). Experiences of Stigma and Discrimination among Adults Living with HIV in a Low HIV-Prevalence Context: A Qualitative Analysis. *AIDS Patient Care and STDs*, 23, 267-276. https://doi.org/10.1089/apc.2008.0168

Part 2: Empirical paper

Supporting mental health professionals in making decisions about disclosure of lived experience: Acceptability and preliminary outcomes of a guided self-help intervention.

Abstract

Background Recent studies have found evidence of high rates of mental health problems amongst mental health professionals. However, the majority of professionals appear not to seek support and appropriate adjustments in the workplace. This might be linked to concerns about negative consequences of disclosure, stigma and shame.

Aims This study aims were: 1. to adapt an existing group intervention into a guided self-help intervention designed to support mental health professionals with lived experience in carefully making disclosure related decisions; 2. to test the acceptability and preliminary outcomes of the new guided self-help intervention.

Method The intervention and evaluation procedures were adapted in collaboration with stakeholders. A small pilot was carried out to seek feedback on the adapted intervention and outcome measures from four participants. Following this, a pilot RCT was conducted to evaluate the acceptability of the adapted intervention and outcome measures, and to assess preliminary outcomes. Data were collected using online surveys and telephone interviews. Fifty-one qualified and trainee mental health professionals completed the baseline survey and 31 completed the post-intervention survey.

Results Acceptability was generally high although participants suggested several areas for improvement. Participants' feedback varied regarding which parts of the self-help intervention they found helpful. The most valued component of the intervention was an anonymous online peer forum which was experienced as supportive and validating. An Intention to Treat analysis revealed mixed results which differed from previous trials of the original peer group intervention. Outcome measures appeared to only partly capture the key benefits participants described in their qualitative feedback.

Conclusions Results indicate that an intervention supporting mental health professionals to carefully weigh up disclosure decisions and engage in discussion with peers can be helpful. However, future research with a larger, more diverse group of participants and suitable outcome measures is required to explore this further. Study limitations and implications are explored.

Introduction

In recent years, an increasing number of studies have found that rates of distress and mental health problems may be high among mental health professionals. The British Psychological Society (BPS) and New Savoy Partnership staff wellbeing survey for 2015 (N = 1106, 88% of whom worked for the NHS) found that almost half of psychological staff reported struggling with depression (46%) and feeling like a failure (49.6%), while 70% were experiencing significant levels of work-related stress and burnout (Rao et al., 2016). Similarly, in a national survey of UK clinical psychology training courses, 67% of trainees (N = 348) reported having lived experience of at least one mental health problem (Grice, 2016), whilst in a national survey of qualified clinical psychologists, 62.7% of respondents (N = 678) reported having lived experience of one or more mental health problems (Tay, 2016). Of these, just over 11% had never disclosed their mental health problem to anyone, 26% reported having disclosed to their employer, and 38% to their colleagues or peers, whilst 68.2% reported disclosing to their family (Tay, 2016).

These disclosure rates suggest that the majority of professionals do not seek support and appropriate adjustments in the workplace when experiencing difficulties with their mental health. Aside from struggling in silence, poor staff health and well-being can also have significant negative effects on staff sickness absence, and thus impact upon sustainable, safe and effective service delivery (Royal College of Physicians, 2015). High levels of work-related stress amongst health professionals are associated with worse quality of care, staff engagement, organisational and patient outcomes (Dawson, 2014; Disability Rights UK, 2014). In addition, lack of open acknowledgement by mental health professionals of their own lived experience contributes to sustaining the 'them and us' divide between professionals and service users, a kind of 'othering' mentality that reinforces social distance and stigma (Garthwaite, 2016).

Reluctance to disclose in the workplace is attributable to both beliefs and experiences of being treated unfavourably and being devalued by employers, and being rejected or excluded by co-workers (Brohan et al., 2012), and there is evidence that

actual disclosure can have negative consequences including negative attitudes and judgments from co-workers, discriminatory treatment in the workplace (Joyce, Hazelton & McMillan, 2007; Joyce, McMillan & Hazelton, 2009), and being treated as less competent or being avoided by others (Schulze & Angermeyer, 2003; Wahl, 1999). It is therefore reasonable to assume that concealment may feel necessary or serve a self-protective function in unsupportive and discriminatory environments (Ragins, Singh, & Cornwell, 2007).

The tendency to conceal one's mental health problems has been linked to higher levels of stigma (anticipated, perceived and self-stigma); high stigma stress (when the perceived threat or harm of stigma exceeds the perceived resources to cope with it); lower perceived social, emotional and practical support; and the perceived benefits of disclosure (Grice, Alcock, & Scior, 2018). For mental health professionals specifically, reluctance to disclose is linked to perceived negative consequences, stigma and shame associated with mental health problems, as highlighted in a scoping report produced for Time to Change, England's largest campaign against mental health stigma and discrimination (Disability Rights UK, 2014).

Some of the key assumptions fuelling stigma and discrimination in the work context include that people with mental health problems lack competence, that they are dangerous, and that they are unable to cope with the stress and demands of working (Krupa, Kirsh, Cockburn, & Gewurtz, 2009). A recent Shaw Trust (2018) survey found that 50% of employers surveyed (N = 550) agreed it was a 'significant risk' to their business to hire someone with a mental health problem, and 42% thought that people with mental health problems are not as reliable as other employees (up from 23% in 2009). Negative attitudes towards people with mental health problems are also widespread among mental health professionals themselves (Hansson, Jormfeldt, Svedberg, & Svensson, 2013) and have been more difficult to shift compared to the general population through anti-stigma campaigns such as Time to Change (Disability Rights UK, 2014), which may further influence mental health professionals' reluctance to

disclose. This indicates that mental health professionals' fears of being viewed or treated negatively if they disclose their mental health problem are not unfounded.

However, concealment has been associated with higher levels of psychological distress (Quinn & Chaudoir, 2009), for example due to fears of 'being found out' by others (Pachankis, 2007), lower self-efficacy (Kleim et al., 2008), reduced feelings of belonging and reduced job satisfaction and commitment (Ellemers & Barreto, 2006; Newheiser, Barreto, & Tiemersma, 2017). It may also limit people from receiving the emotional and practical support they need; for example, disclosure may be required to obtain 'reasonable adjustments' in the workplace (Brohan et al., 2012).

Correspondingly, disclosure of a concealable stigmatised identity such as a mental health problem can have advantages such as increased emotional and social support (Smith, Rossetto, & Peterson, 2008; Weisz, Quinn, & Williams, 2015). In addition, more positive beliefs about the benefits of disclosure are associated with a greater sense of empowerment and improved quality of life (Corrigan et al., 2010), whilst reflecting on the pros and cons of disclosure, learning about different disclosure strategies and developing a personal disclosure narrative in a group setting can reduce the more harmful aspects of self-stigma and stigma stress (Corrigan et al., 2015; Mulfinger et al., 2018). Integrating rather than separating a stigmatised identity such as a mental health problem from one's other identities can also be helpful in one's professional practice. For example, mental health professionals with personal experience of mental health problems who demonstrate a more integrated patientprofessional identity might be better able to draw on concepts of 'personal recovery' and 'wounded healer' than those who keep their dual identities separate, increasing the potential for the positive application of their lived experience to their work (Richards, Holttum and Springham, 2016).

In this context, one could argue that increased openness around mental health problems could be one useful strategy for improving staff support and well-being, whilst reducing people's sense of isolation and anxiety about being found out. In addition, increased disclosure could contribute to reducing public stigma (Corrigan & Bink, 2016).

However, it is important to acknowledge that disclosure-related decisions can be influenced by many contextual factors which differ for each individual. For example, people with some mental health problems, such as schizophrenia and substance use disorders, experience more stigma (Crisp, Gelder, Rix, Meltzer, & Rowlands, 2000) and overt discrimination than others (Dinos, Stevens, Serfaty, Weich, & King, 2004) which could influence their inclination to disclose. Supportive work environments are needed to enable psychological professionals to disclose and access appropriate help and support if they wish to do so. Positive work environments have been associated with reduced disclosure-related fears and higher rates of disclosure (Ragins et al., 2007).

Existing interventions that aim to support people in making disclosure-related decisions include the 'Conceal Or ReveAL' (CORAL) decision aid, a brief tool designed to assist people with mental health problems in weighing up reasons for and against disclosure in an employment context which can be completed in around 30 minutes (Henderson et al., 2012, 2013), and 'Honest, Open, Proud' (HOP) (Corrigan, Kosyluk, & Rüsch, 2013; Rüsch et al., 2014). HOP is a three-session (plus booster) peer group intervention designed to support people in thinking through the advantages and disadvantages of disclosure versus concealment of their mental health problems in different contexts, evaluating different strategies for disclosure, and developing a personal disclosure story. The primary aim is to help people carefully reach a decision as to whether or not they want to disclose their difficulties in different settings and to different people, and to help reduce self-stigma and stigma stress. The HOP programme acknowledges that disclosure is a personal decision which is not right for everyone and does not push people to disclose.

A pilot randomised controlled trial (RCT) of HOP found that participants showed significant decreases in their levels of stigma stress, secrecy and disclosure-related distress and agreed more strongly with the perceived benefits of disclosure compared to controls, although some of these effects slightly diminished during the 3-week follow-up period (Rüsch et al., 2014). More recent RCTs of HOP found that HOP participants made significant improvements in stigma stress appraisals, self-stigma, disclosure-

related distress, and on other measures of mental health and attitudes towards disclosure and concealment (Mulfinger et al., 2018), and in the more harmful aspects of self-stigma related to diminished self-esteem (Corrigan et al., 2015).

The current study aimed to adapt HOP into an intervention suitable for mental health professionals in light of concerns around high levels of distress, stigma-related stress and difficulties seeking support. As a group intervention was deemed unsuitable for this population due to aforementioned evidence of reluctance to disclose openly within professional circles, it was decided to adapt the HOP programme into a guided self-help intervention named 'Honest, Open, Proud for Mental Health Professionals' (HOP-MHP), and to retain the element of peer support by creating an anonymous web peer forum for study participants.

As HOP supports participants to take the time to reflect on disclosure in a nuanced way (Rüsch et al., 2014) rather than seeing it as an all-or-nothing approach, we expected that this would allow participants to be clearer about their options and resources and to feel more confident and comfortable with making disclosure-related decisions, thus reducing stigma stress and disclosure-related distress. It was also anticipated that the intervention would lead to a reduction in the tendency to keep one's mental health problem secret and reduce distress and worry associated with feeling one has to sustain a concealed identity. In addition, the intervention was expected to increase the perceived benefits of disclosure. Finally, it was hoped that the peer support element would reduce participants' levels of stigma stress by increasing social support and normalising their experiences.

The HOP-MHP project is supported by the British Psychological Society and is a pathfinder project for their Collaborative Learning Network which was launched as a result of the Charter for Psychological Staff Wellbeing and Resilience (The British Psychological Society and New Savoy Conference, 2016).

Aims

This project aimed to assess whether a guided self-help intervention adapted from the existing HOP group intervention is acceptable, feasible and efficacious for qualified and trainee mental health professionals.

The aims of this study were as follows:

- To adapt HOP into a guided self-help intervention aimed at mental health professionals.
- To evaluate the acceptability and feasibility of HOP-MHP using qualitative feedback.
 As this was a joint project, the present article focuses on the acceptability of the intervention and outcome measures whilst my colleague's focuses on feasibility.
- 3. To evaluate preliminary outcome data regarding the efficacy of HOP-MHP. This included one shared primary outcome measure of 'Stigma Stress', and several secondary outcome measures specific to this part of the project focusing on extent of disclosure, disclosure-related distress, secrecy, and perceived benefits of disclosure.

Method

Study design

This study was comprised of three stages (each outlined below in more detail). An overview of the different numbers and types of participants involved at each stage is provided here. In the first stage, there were 15 stakeholders (14 qualified and trainee clinical psychologists and one member of the clinical psychology pre-qualification group who also held a position as a peer support worker) who aided with the development of the self-help guide and research procedures. In the second stage, four trainee clinical psychologists provided feedback on the adapted self-help guide and outcome measures.

The third stage consisted of a mixed methods pilot RCT. A 2 x 3 (group x time) mixed factorial design was employed using a range of standardised measures in an online survey which participants in the intervention and control groups were asked to complete at three different time-points. However, due to the limited number of participants who completed the survey at the third time-point, only quantitative data from the first two time-points was used in the analysis (effectively making it a 2 x 2 mixed design).

51 participants were allocated to either the intervention (N=26) or control group (N=25) after completing the baseline survey (T0). Of these, 31 participants (13 intervention and 18 control participants) completed the second survey (T1), and 13 (five intervention participants and eight control participants) completed the final survey (T2).

Participants were also asked to provide qualitative feedback. At T1, 13 intervention participants provided qualitative feedback regarding the overall intervention, 11 provided feedback on the peer forum, and 31 participants from both groups provided feedback regarding the outcome measures. At T2, five intervention participants provided feedback about the intervention, four responded to questions about the peer forum, and 14 participants from both groups responded to questions about the measures. Three participants from the intervention group participated in semi-structured telephone interviews to provide more detailed qualitative feedback.

Stage 1: Planning and development work (April 2016 – May 2017)

This stage focused on the development and adaptation of the original HOP group intervention into a guided self-help intervention. Once the project received approval from the UCL Research Ethics Committee (Project ID No.: 9297/002, Appendix C), a stakeholder group was set up by contacting clinical psychologists who previously registered their interest in being involved in follow-up work to a previous study on mental health problems among clinical psychologists (Tay, 2016), and contacting clinical psychology training courses who participated in a previous study on disclosure of mental health problems (Grice, 2016). Stakeholders were invited to attend a whole day meeting to help guide the adaptation process.

The stakeholder meeting day focused on three objectives:

- (1) Adaptation of the HOP manual and workbook into a self-help intervention for clinical psychologists and other mental health professionals.
- (2) Discussion of proposed procedures for piloting and evaluation of the new HOP selfhelp intervention.
- (3) Identification of other resources that would need to be available alongside the intervention, such as information about accessing support, availability of a web peer forum and support from the BPS/DCP.

After a brief presentation of the study aims, stakeholders were split into groups of three to four and, facilitated by a member of the research team, each group worked through a different session of the original HOP manual and workbook to generate ideas for how to adapt the content and language. The groups were facilitated in line with consensus methods, mostly drawing on Nominal Group Technique (NGT) (Centers for Disease Control and Prevention, 2006; McMillan, King, & Tully, 2016). NGT provides a systematic way of generating and discussing ideas in small groups and rating them using private voting. This helped establish priorities and attain group consensus in a systematic way. The remainder of the day involved a large group discussion of the second and third objectives.

Proposed changes were implemented and the adapted HOP-MHP guide was reviewed by six stakeholders, with at least one stakeholder from each small group reviewing the session they had originally worked through. Their final comments were addressed before proceeding to the next stage. Outcome measures were also adapted to make them more suitable for the target population, taking into account stakeholder comments. To retain the peer group element of the original HOP group intervention and with stakeholder consensus, a decision was made that it would be crucial to set up an anonymous, moderated web peer forum.

Stage 2: Brief pilot of the adapted HOP self-help workbook (June to August 2017)

A small pilot was carried out in order to assess the acceptability and feasibility of the adapted self-help guide and evaluation methods. One qualified and four trainee clinical psychologists were recruited using convenience sampling in the form of an email that was sent to the UCL training cohorts and to stakeholders involved in the previous stage who had not reviewed the adapted guide, although only the four trainees provided feedback. Participants were asked to complete the self-help guide and all outcome measures, and then received a brief email survey asking for feedback concerning their content, structure, language, length, accessibility and impact. Participants were also asked to comment on any adverse effects and whether they thought the intervention was suitable for use by a range of mental health professionals. Any issues raised by participants were addressed prior to the next stage as far as possible. Concurrently to the small pilot, the web peer forum was created using free 'Slack' software and a study website was set up providing resources and information on how to access support and psychological therapy and signposting to external organisations that advise on professional guidelines around fitness to practice and employment (legal) rights (https://www.ucl.ac.uk/pals/hop-mhp-project-0).

Stage 3: Pilot Randomised Controlled Trial (RCT) for feasibility and preliminary outcome data (September 2017 to April 2018)

In line with the Medical Research Council's guidance on developing and evaluating complex interventions (Craig et al., 2006; Moore et al., 2014), the aim of this

stage was to assess the feasibility, acceptability and preliminary outcomes of the HOP-MHP intervention (the self-help guide plus the web peer forum) for this population, as well as the feasibility of conducting a trial using this intervention. As this thesis focuses on acceptability whilst my colleague's focuses on feasibility, only the acceptability questions this study attempted to answer are outlined here. Acceptability of the intervention was evaluated by using the following five categories (Sidani & Braden, 2011) as a framework for the qualitative data:

- Appropriateness of the content of the intervention in relation to the 'presenting problem' it is designed to address (i.e. is the content congruent with the stated aims of the intervention?);
- Convenience or ease of use (e.g. accessing and completing the intervention and surveys and the time taken to do this);
- 3. Effectiveness or helpfulness of the intervention;
- 4. Adverse effects or risks, and barriers to participation;
- Adherence (e.g. attrition rates and proportion of the guide and worksheets
 participants completed). This area is only briefly touched upon as it is explored in
 more detail in the feasibility study of this project.

Power analysis.

G*Power 3.1 (Faul, Erdfelder, Lang, & Buchner, 2007) was used to conduct a power calculation for a repeated measures ANOVA, within-between interaction, based on Rüsch et al.'s (2014) findings on the 'Stigma Stress' measure which yielded an effect size of partial η^2 =0.10 between baseline and post-intervention. The following input parameters were entered: f = 0.33 (equivalent to partial η^2 =0.10), alpha = 0.05, 80% power, correlation between repeated measures = 0.5 and non-sphericity correction = 0.75. The calculation yielded an estimated overall sample size of 20 participants. However, as replication studies often do not achieve the same power as the original study (Button et al., 2013) and self-help interventions tend to have smaller effects than therapist-administered interventions (Lewis, Pearce, & Bisson, 2012), the estimated total sample size was increased to 40 participants. Additionally, taking into account dropout

rates of 20-25% reported by other RCTs of self-help interventions (Christensen, Griffiths, & Jorm, 2004) and HOP (Rüsch et al., 2014), the recruitment target was adjusted to an overall sample of 50 participants (25 per group).

Participants.

Participants were recruited by emailing UK clinical psychology training course directors and Improving Access to Psychological Therapies (IAPT) High Intensity CBT training courses and asking them to circulate study information to staff, students and alumni. In addition, the study was advertised via various social media accounts, the study website, in a blog post on the BPS website and in a newsletter on the North West Psychological Professions Network website. We originally planned to recruit via the DCP mailing list (as in Tay's 2016 study) as the DCP had agreed to circulate information about our study to its members; however, they did not follow through on this agreement. *Inclusion criteria*

- Qualified or trainee mental health professionals in the UK; who
- Report past or current experiences of mental health problems (both self-identified and formally diagnosed); and
- Are not already fully 'out' about their experiences of mental health problems (i.e. if they had not disclosed these widely in all or most areas of their life)

Exclusion criteria

High in self-harm or suicidal ideation, measured as selecting the highest score
 ('nearly every day') on item 9 of the PHQ-9 (Kroenke, Spitzer, & Williams, 2001):
 "Over the last 2 weeks, how often have you been bothered by thoughts that you
 would be better off dead or of hurting yourself in some way?" Anyone who selected
 this was informed that at the present time they were not suitable for the intervention
 and signposted to information about accessing support and crisis services.

Participants were screened for eligibility at the point at which they consented to participating in the study (four brief screening questions were added below the consent form) and again in the baseline survey which contained a broader range of questions about their experience of mental health problems amongst other sociodemographic

questions. Overall, 61 participants submitted their consent form and were eligible for the study. Of these, 51 completed the baseline survey and were randomly allocated to either the intervention (N=26) or control group (N=25).

The intervention group included 21 female and five male participants, and the majority (n = 24) identified their ethnicity as 'White British / White Other', whilst one person identified as 'Asian / British Asian' and one person selected 'Other' without stating their ethnicity in the text box. The control group consisted of 23 females and two males; all control participants indicated they were 'White British / White Other'. The intervention group included 13 qualified and 13 trainee mental health professionals, whilst in the control group 12 participants were qualified and 13 were trainees. Although the majority of sample consisted of qualified and trainee clinical psychologists (18 per group), each group contained a number of other mental health professionals (eight in the intervention group, and seven in the control group). There were no significant differences between the psychologists and other mental health professionals in terms of demographic characteristics, quantitative responses or qualitative feedback provided and they were therefore included in the analysis. An overview of additional participant characteristics can be found in Table 1 below.

Setting.

Participants accessed the self-help guide and peer forum remotely as the materials and login details were provided via email. Outcome measures were accessed using web-based Qualtrics surveys. Semi-structured qualitative interviews took place over the telephone. There was no face-to-face contact with participants.

Measures.

All participants were asked to provide brief sociodemographic data at baseline (age group, gender, ethnicity, sexual orientation, profession, qualification status and years since qualifying/year in training). They were also asked to describe their understanding of their past and/or current mental health problems, if they had ever received a formal diagnosis and whether they had sought any professional help.

Table 1

Demographics*

	Intervention (N=26)	Control (N=25)
Age group	18-24 years = 3 25-34 = 15 35-44 = 5 45-54=2 55-64=1	18-24 years = 2 25-34 = 14 35-44 = 6 45-54=1 55-64=1 65+=1
Sexual orientation	Bisexual = 5 Heterosexual = 19 Homosexual = 2	Bisexual = 5 Heterosexual = 17 Homosexual = 2 Other = 1 ("Don't adhere to any groupings")
Profession (qualified & in training)	Clinical Psychologist = 18 IAPT Therapist = 3 Mental Health Nurse = 2 Psychotherapist = 1 Social Worker = 1 Recovery worker = 1	Clinical Psychologist = 18 IAPT Therapist = 2 Mental Health Nurse = 2 Mental Health Social Worker = 2 Chaplain = 1
Current mental health problem**	Yes = 6 No = 20	Yes = 8 No = 17
Past mental health problem**	Yes = 26	Yes = 24 No = 1
Professional help sought	Yes = 24 No = 2	Yes = 24 No = 1
Given a formal diagnosis?	Yes = 20 No = 6	Yes = 12 No = 13
Diagnoses given (past and present)	 n = 20 responses*** Adult Attention Deficit Hyperactivity Disorder = 1 Anorexia Nervosa = 5 Bulimia = 1 Anxiety = 8**** Complex Post-Traumatic Stress Disorder (C-PTSD) = 2 Dissociative Disorder = 1 Depression = 14***** Emetophobia = 2 Emotionally Unstable (or Borderline) Personality Disorder (EUPD) = 5 Schizoaffective disorder = 1 Trichotillomania = 1 Obsessive Compulsive Disorder = 3 	 n = 12*** Anorexia Nervosa = 2 Anxiety = 8**** C-PTSD = 2 Dissociative Disorder = 1 Depression = 9***** Eating Disorder-Not Otherwise Specified = 1 EUPD = 5 IBS = 1 Panic disorder = 1

^{*}Only categories with ≥1 response are listed here rather than showing all survey options

^{**}For purposes of this survey this referred to "psychological, emotional and/or behavioural difficulties that have diminished your capacity for coping with the ordinary demands of life. This includes but is not limited to mental health problems as defined by DSM or ICD criteria, and is regardless of whether or not you have received a formal diagnosis."

^{***}Almost every participant who responded to this question provided multiple diagnoses. The numbers stated here represent how often each diagnosis was mentioned.

^{****} Including "chronic anxiety", "anxiety, type not specified", "generalised anxiety disorder" and "social anxiety"

^{*****} Including responses such as "depression", "recurrent depression" and "major depressive disorder"

Participants were asked to complete the same battery of standardised measures before the start of the self-help intervention (baseline), after completing the three core sessions of the guide (T1), and after completing the follow-up session (T2). The measures were designed to assess experiences relating to mental health stigma, disclosure and disclosure-related distress, depression and anxiety and were estimated to take less than 20 minutes to complete.

As this study is a joint trainee project, the outcome measures were divided between the two projects except the shared primary outcome measure 'Stigma Stress' and the sociodemographic data. This project focused on the outcomes measures described below.

Stigma Stress. The Stigma Stress Scale (Rüsch et al., 2009a; Rüsch et al., 2009b) is an eight item measure with good internal consistency (α = .77 - .91 for the two subscales as measured in Rüsch et al., 2014). The first four items measure an individual's appraisal of mental health stigma as harmful to them, while the latter four items measure their appraisal of their perceived resources to deal with stigma. Items are scored on a 7-point Likert scale, with higher mean scores indicating greater perceived harm or coping resources. An overall stigma stress appraisal score is calculated by subtracting mean scores of the 'perceived resources' subscale from the mean scores of the 'perceived harmfulness' subscale. Higher discrepancy scores (range -6 to +6) indicate higher stigma stress levels, with scores above zero indicate that the individuals perceived threat or harm of stigma exceeds their perceived resources to cope with it (Rüsch et al., 2009b). We adapted this measure by adding two items to each subscale specific to our target population and making minor language changes in line with stakeholder feedback, for example by changing 'with mental illness' to 'experiencing mental health problems'.

Secrecy. The Secrecy Scale (Link, Struening, Neese-todd, Asmussen, & Phelan, 2002) is a measure of an individual's beliefs about the need to keep one's mental health problems secret. It has good internal consistency ($\alpha = .84$) as measured

by Rüsch et al. (2014). It contains nine items rated from 1 (strongly disagree) to 4 (strongly agree). Higher mean scores indicate a stronger tendency towards secrecy.

Likelihood of disclosure. The Disclosure of Lived Experience scale (DOLE; adapted from Grice, 2016 who adapted it from Rüsch et al., 2014): This measure comprised 11 items scored on a 7-point Likert scale to assess the likelihood of disclosure to 11 different recipients: 1. family member, 2. close friend, 3. acquaintance, 4. member of course staff (if still in training), 5. clinical supervisor, 6. line manager, 7. a colleague, 8. a fellow trainee (if still in training), 9. health professional (e.g. GP), 10. client I am seeing, 11. service user groups. Participants were also able to respond: 'I've already disclosed to them' and 'Not applicable' and those responses were excluded from the analysis. Mean scores were calculated for four subscales comprising the 11 recipient categories: Social (recipients one to three), Professional (recipients four to eight), Healthcare professional (recipient nine) and Service users (recipients 10 and 11). Higher mean scores indicated higher likelihood of disclosure. As HOP is designed to help people carefully think about the pros and cons of disclosure versus concealment in different contexts, and identify the strategy most beneficial to them, a 'successful' outcome depends on what is acceptable and helpful to the individual which can make it difficult to interpret the results of this measure. Psychometric values are not available for this scale at present

Disclosure-related distress. The Disclosure-related distress measure was adapted from a single item used by Rüsch et al. (2014) to assess an individual's level of distress and worry in relation to secrecy or disclosure of their mental health problems to other people. The original item was: 'In general, how distressed or worried are you with respect to secrecy or disclosure of your mental illness to others?', rated on a 7-point Likert scale with higher scores indicating higher levels of distress or worry. This item was adapted into the following two items: 'How distressed or worried are you about keeping your mental health problem/s secret from the following people?' and 'How distressed or worried are you about the following people finding out about your mental health problem/s?' which participants were asked to rate from 1 (not at all) to 7 (very

much) in relation to the same 11 types of people as described above for the DOLE scale. Participants were also able to respond: 'I've already disclosed to them' and 'Not applicable' and those responses were excluded from the mean score computations.

Psychometric values are not available for this scale at present

Perceived benefits of disclosure. The Coming Out with Mental Illness Scale (COMIS; adapted from Corrigan et al., 2010) measures participants' perceived benefits of disclosing versus reasons for concealment. It has acceptable internal consistency (α = .76 – .78 as measured in Rüsch et al., 2014 across three different time points). Participants were initially asked whether they have already disclosed to most of their social network (yes = 1, no = 2), which was used as a measure of their 'extent of disclosure', and depending on their response were presented with a different subset of items. Those who responded 'yes' were asked to what extent they agreed with a range of reasons for or benefits of disclosing their mental health problems (11 items, four of which were added to the original scale) and reasons for concealing their mental health problems in the past (16 items, two of which were added to the original scale). Those who respond 'no' to the initial item were presented with items asking to what extent they agreed with a range of benefits of disclosing in the future (11 items, adapted as above) and a range of reasons for why they were currently concealing their mental health problem (16 items, adapted as above). Items were scored on a 7-point Likert scale, with higher mean scores indicating stronger agreement with benefits of disclosure or reasons for concealment. The items yielded two overall subscales: 'benefits of being out' and 'reasons for staying in'. The language of the original measure was adapted, for example by changing 'came out of the closet' to 'disclosed'.

Satisfaction. The Satisfaction with Treatment (SAT; adapted from Richards & Timulak, 2013) measure was designed to assess participants' experience of the self-help guide, peer forum and outcome measures, using a mixture of Likert scales (some ranging from 1 to 4, some from 1 to 5) and open comment boxes covering the aspects outlined earlier under the acceptability criteria.

Apart from the DOLE and SAT measures, the measures were all based on or adapted from those used in Rüsch et al.'s (2014) study to allow for comparison of results. The semi-structured telephone interviews focused on the acceptability, process and impact of using the self-help guide and peer forum.

Procedure.

Recruitment information contained a brief overview of the study and a link to the study website which provided further details about the background to the project, the information sheet (Appendix D), consent form and brief screening questionnaire (Appendix E), and information about sources of support. Participants were advised in the information sheet to create a new alias email address with which to sign up to the study if they wanted to remain anonymous.

Eligible participants were allocated a participant number (e.g. P1, P2, etc.) and were sent a personalised link to the baseline survey (T0) tracking their progress. Those who completed T0 were then allocated consecutive 'HOP numbers' (e.g. HOP1, HOP2, etc.) which had been pre-randomised to either the intervention or the control group in advance of the pilot RCT. The participant numbers and HOP numbers were allocated by a research assistant and the researchers were not involved until a participant was allocated to a study arm.

Next, participants in the intervention group were provided with the three core sessions of the self-help guide and peer forum login details. It was anticipated that participants would complete these sessions within three weeks (with an estimated 1 to 1.5 hours for each session), a period in which some self-help interventions have shown effectiveness (e.g. Sethi, Campbell, & Ellis, 2010) and which is in line with the time scale used in the original HOP intervention.

Weekly reminder e-mails were sent to participants in the intervention group (for three weeks), whilst control participants received weekly 'keeping in touch' emails (for three weeks). After the initial 3 weeks, all participants were sent different emails depending on their progress with the intervention and/or surveys in accordance with their allocated group (see Appendix F for a flowchart overview). Participants who did not

respond to the surveys and reminder emails, and those in the intervention group who did not confirm that they had completed the respective part of the guide they were working through or inform researchers they needed more time, were sent an email asking if they wished to continue with the study, and if there was no response within two weeks of this email they were marked as 'dropped out' and sent a brief dropout survey; however, if they got in touch at a later point asking to continue with the study they were able to do so.

Participants in the intervention group were able to consent to taking part in the telephone interviews in the final survey (T2); however, as only a small number had progressed to T2 it was decided later in the study that all intervention participants who had completed the T1 survey would be asked if they wanted to take part in a telephone interview. Those interviews were audio recorded and transcribed. Telephone interviews lasted approximately 40 minutes and aimed to flexibly cover the areas outlined on the interview schedule. Control participants were provided with the full self-help guide (three core sessions and follow-up sessions) and login details to the peer forum after they had completed the T2 survey.

The intervention.

The original HOP program comprised three group sessions. A follow-up or booster part was developed later on. Materials consist of a participant workbook and corresponding facilitator manual (original materials can be viewed on: http://www.hopprogram.org). For this study, the facilitator manual and participants workbook were combined into one self-help guide containing the three core sessions and a separate follow-up session (see Appendix G for cover and content pages). The adapted self-help guide followed a similar structure to the original and retained its 'key ingredients' but the language and specific examples were changed to suit an audience of British mental health professionals.

The three core sessions of the adapted self-help guide are as follows:

1. Considering the Pros and Cons of Disclosing: this session involves thinking about one's identity and one's attitudes towards mental health problems, and weighing up the

risks and benefits of disclosure.

- 2. There are Different Ways to Disclose: this session involves considering different strategies of disclosure and weighing up their pros and cons, who might be a suitable person to disclose to, how others might respond to a disclosure and how their response might impact upon oneself.
- 3. Sharing Your Experiences.: this session supports participants to construct a meaningful narrative about their mental health problems, consider options for peer support and decide how to move forward with disclosure.

The follow-up session comprises four sections:

- a. *The Decision to Disclose*: reviewing disclosure decisions and experiences since completing the core sessions of the guide.
- b. *Peer Support*: exploring experiences of peer support since engaging with the guide.
- c. What Has Changed?: revisiting costs and benefits of disclosure, reviewing goals of disclosure and one's disclosure story.
- d. What Next: reflecting on next steps on one's journey as decisions around disclosure are a continuous process rather than a single event.

In addition, the adapted guide contained a preface with background information about the study and intervention, a disclaimer recognising different language preferences for describing 'mental health problems', an acknowledgement that disclosure decisions have to suit the individual in their given context and require careful consideration, and signposting to resources for managing distress.

Researcher's stance towards disclosure.

The intervention was intended to encourage participants to weigh up the pros and cons is disclosure in a balanced way. The self-help guide included a clear discussion around disclosure not being the most helpful choice for every person or in every context and highlighted that it is very much an individual choice. However, it should be acknowledged that the researchers generally have a positive attitude towards disclosure and hold the view that a more open discussion of mental health problems among mental health professionals could be a helpful step towards reducing stigma

within the profession and wider society. Therefore, whilst researchers attempted to approach data collection and data analysis in an unbiased manner, it is possible that positive beliefs and attitudes towards disclosure influenced the analysis or interpretation of the data.

Data analysis.

The quantitative data were analysed using IBM SPSS Version 22. As participants were randomly allocated to their respective groups, no tests were conducted for differences between the groups at baseline in line with the CONSORT (Consolidated Standards of Reporting Trials) statement (Moher et al., 2010) which posits that in a randomised trial, any significant differences between groups in terms of their baseline characteristics would be due to chance (as opposed to bias), and that a table showing relevant characteristics of each participant group is the most useful way of presenting this information. Mixed design ANOVAs were carried out to compare differences in outcomes between the two group over time, using data collected at T0 and T1, with *condition* (intervention vs control) as the between-subjects factor and *time* (T0 to T1) as the within-subjects factor. The mixed ANOVA allowed detection of any significant group x time interaction. Effect size estimates (Cohen's *d*) were computed for all measures.

As only 31 participants had completed the T1 survey at the time data collection ended for this project, an intention-to-treat (ITT) analysis was carried out to reduce bias (as those who had progressed to T1 were more likely to be participants who had benefited from the intervention) using the Last Observation Carried Forward (LOCF) method (Gupta, 2011). Results from an ITT analysis produce more conservative results but can be considered more representative of the actual effects of an intervention as they are inclusive of those whose adherence was negatively affected in some way, as is usually the case with any treatment, and therefore increases generalisability of the results beyond the study sample (Gupta, 2011). Only data for participants who had been marked as 'dropped out' of the study were added into the ITT analysis (n = 10). Those who were still in progress were excluded from the ITT analysis at T0 and T1 (n = 10).

Data for T2 was not included in the ANOVAs due to limited survey completion rates in the intervention group.

Qualitative data from the SAT questionnaires at T1 and T2 and the telephone interviews were collated and analysed using deductive or theory-driven thematic analysis, i.e. focusing on specific aspects of the data that mapped onto the pre-existing acceptability questions as a thematic framework and on the explicit (semantic) meaning of the data (Braun & Clarke, 2006). The satisfaction ratings from the SAT questionnaire were analysed descriptively and reported in conjunction with the qualitative data to help answer questions around acceptability.

Results

At the cut-off point for data collection, 51 participants had completed the baseline survey (T0). Of these, 26 had been randomly allocated to the intervention group and 25 to the control group. 31 participants had completed the T1 (13 intervention and 18 control participants), and 13 participants had completed the final T2 survey (five intervention and eight control participants).

All participants, regardless of whether or not they had received a formal diagnosis, provided an account of their personal understanding of their mental health problem. The descriptions tended to be detailed (see Appendix H for a selection of quotes from these accounts).

Qualitative data

Descriptive results from the SAT surveys and a summary of the main themes along with illustrative quotes shared by participants in the telephone interviews and SAT surveys are provided below, whilst a summary of additional participants' quotes can be found in Appendix I. At T1, 13 intervention group participants responded to SAT questions regarding the intervention, 11 responded to questions about the peer forum, whilst 31 participants from both groups responded to questions about the outcome measures. At T2, five intervention participants responded to SAT questions about the intervention, four responded to questions about the peer forum, and 14 participants from both groups responded to questions about the measures.

1. Appropriateness of the intervention in relation to its stated purpose (i.e. is the content coherent with the stated aims of the intervention).

Intervention group participants were not asked explicitly to rate or comment on their perception of the appropriateness of the intervention, but this has been inferred based on their overall satisfaction ratings and relevant comments. At T1, 84.6% of respondents to the SAT questionnaire reported they were either 'satisfied' or 'very satisfied' with the overall intervention, with M = 4.08 (SD = 0.64) out of a maximum score of '5' (maximum scores are henceforth denoted by '/' within the mean score brackets). 92.3% of respondents indicated that they would recommend the intervention

to others (M = 4.31 / 5, SD = .63). At T2, 80% of respondents were either 'satisfied' or 'very satisfied' with the overall intervention (M = 4 / 5, SD = 0.71) and 60% reported that they would recommend it to others (M = 3.8 / 5, SD = 0.84), whilst 40% were undecided.

Participants remarked that the intervention was comprehensive and validating, indicating that the content and tone were generally appropriate.

"[I liked] its comprehensiveness, I liked hearing others' experiences in the peer forum, it was comforting to hear others having similar thoughts/doubts/worries etc. I liked how balanced the guide was." [P5]

"And the sort of tone of it, and what it was pitched at, and I found myself reading through some of it and thinking "Oh yeah, I think that" and "Oh yeah, I think that", and that felt really validating, actually." [P27]

However, its comprehensiveness resulted in some of the content being too broad and some parts being more or less helpful than others.

"It maybe explains more than it would need to for clinical psychologists but sometimes it's good to be reminded of the basics." [P2]

"So, there were bits that didn't feel particularly relevant... and then there were other bits that I read and I thought "Oh, I didn't even realise that that was something that could be relevant or interesting, or maybe I could take things to supervision that I haven't thought about". [P27]

The three participants who completed a telephone interview all thought the intervention would be appropriate and suitable for use with a range of mental health professionals, although one suggested this would be conditional on aspects of their professional training characteristics.

"Yeah, I think so actually. (...) I didn't think it was like overly psychologised or overly medicalised, so I think it probably would fit across." [P27]

"I think it's useful for a range of professionals but it probably depends on, I think, how much reflexivity is built into their respective professions as to how accessible an intervention like this is or isn't (...)" [P2]

Participants' feedback regarding the impact of the intervention provided indicated that they found it useful in helping them consider new ways of disclosing.

"It was nice to see the pros and cons [of disclosure] spelled out because the more I

"I think before I had kind of made a de facto decision to disclose in certain ways; now I feel that potentially more options are available to me which is positive." [P35]

This will be explored further in section 3 ('Effectiveness or helpfulness') below.

know about my anxieties the more informed my choices are." [P2]

2. Convenience of the intervention and outcome measures.

At T1, 92.3% of responders indicated that they found the intervention easy to access (M = 4.38 / 5, SD = .87), 76.9% reported they found it easy to complete (M = 4.00 / 5, SD = 1.08), and 53.8% were happy with the recommended time frame to complete the three core sessions (M = 3.46 / 5, SD = 1.20), whilst 30.8% disagreed that they were satisfied with the suggested time frame and 15.38% were undecided. At T2, 80% of responders indicated that they found the intervention easy to access (M = 3.80 / 5, SD = .45), 60% reported they found it easy to complete (M = 3.40 / 5, SD = .89) and 60% indicated they were happy with the recommended time frame for the follow-up session (M = 3.20 / 5, SD = 1.10).

Some participants felt that it was difficult to complete the intervention due to its length and detail, whilst others felt that participating in the intervention was the start of a longer-term process beyond the time-frame of the study.

"I did not feel working in a very busy secondary care MH service, where I already have a backlog of work and regularly stay late, it was very realistic for me to read large quantities of material. Despite it being very interesting and worthwhile I just found the exercises not accessible for someone in my position." (P35)

"It's a process and it's quite a long-term thing, so I think maybe it just needs a lot more time than a few weeks. (...) So, I think it's helpful to run through it in those few weeks but also with the expectation that actually some of that will need much more time. And I guess that's something you do touch on in the guide anyway." [P6]

The time spent completing the guide varied between participants according to feedback from telephone interviews, from one hour per session to an hour and a half for all three core sessions. This appeared linked to how motivated participants felt to properly complete the worksheets and exercises depending on their perceived relevance.

"As soon as I'd given myself permission to only complete the bits that felt relevant, it wasn't something I needed to avoid. And I think the advice I would give other people is to do a skim read of the lot when it arrives because that would have certainly reduced my procrastination because it wasn't an onerous as I was expecting it to be." [P2]

In terms of the outcome measures, a majority of respondents at T1 reported that they were happy to complete the outcome measures at the different time points (74.2% agreed or strongly agreed, M = 3.68 / 5, SD = .91), with the time taken to complete the measures (71%, M = 3.58 / 5, SD = .99), and that they found them easy to complete (71%, M = 3.71 / 5, SD = .90). At T2, 71.4% of respondents indicated they were happy to complete the outcome measures, 64.3% were happy with the time taken to complete them, and 64.3% said they found it easy to complete the measures and web survey.

Participants reported that they thought that the outcome measures were "thoughtfully selected" [P2] and "well set out, very clear" [P18]. They also commented that it was convenient "having options to choose from" [P55] and that the web survey was "very user friendly and not too many/too long" [P42].

However, four respondents mentioned that they perceived the measures as repetitive and eight that they thought the survey was quite long or took too much time to complete. Additionally, several participants expressed confusion over how to respond to some of the items.

"I found the wording of the 2 questions relating to distress and keeping a secret vs being found out confusing and am not sure I answered the question that was intended." [P31].

3. Effectiveness or helpfulness.

On a Likert-type scale from 1 (not at all helpful) to 4 (helpful), 92.3% of respondents rated the intervention as either 'helpful' or 'very helpful' (M = 3.08 / 4, SD = 1.00 / 4)

.49) at T1. In relation to the peer forum, 54.5% of respondents reported that they thought the peer forum in combination with the self-help guide was either 'very useful' or 'useful', whilst 27.27% rated the combination as 'somewhat useful' (M = 2.64 / 4, SD = 1.12). When asked how useful the peer forum was as a resource separate to the guide, 72.2% of respondents rated it as 'very useful' or 'useful' and 18.18% as 'somewhat useful' (M = 3.00 / 4, SD = 1.00). For the overall intervention, 46.2% of respondents said that they thought it would have a lasting effect (M = 3.46 / 5, SD = .97), whilst another 38.46% were undecided about this at T1.

At T2, 80% of respondents rated the intervention as helpful (M = 2.80 / 4, SD = .45). 75% of respondents indicated that they thought the peer forum would be 'very useful' or 'useful' both as a separate resource (M = 3.25 / 4, SD = .96) and in combination with the self-help guide (M = 3.00 / 4, SD = .82). Finally, 60% of respondents thought the intervention would have a lasting effect (M = 3.4 / 5, SD = 0.89), whilst 20% were undecided on this and 20% did not think it would have a lasting impact upon them.

Participants reported that the intervention helped them to reflect on their previous approach to disclosure and feel more confident about making disclosure-related decisions, and reduced their sense of isolation and perceived need for concealment.

"I think [the guide] actually brought it to my attention that actually it is a choice and also, it's okay to not necessarily disclose to anyone and that there isn't any pressure. (...) So yeah, definitely, I think I feel much more confident, especially with the choice to not necessarily disclose, I think it's just sort of validated that a little bit for me." [P6]

"It made me feel a little bit less isolated as a dual status professional." [P2]

"I think there has always been a big part of me that's thought erm, when I feel stressed about things that I need to just manage them and at work be very professional, and very competent and very together, and something about this study, but probably also just feeling really quite stressed generally, has made it feel a bit more okay to be stressed

and talk about it and not feel like I have to manage things on my own... erm, which has almost felt a bit like a revelation." [P27]

Additionally, participants expressed different preferences with regards to which parts of the intervention they found more or less helpful:

"What I found really helpful was the different ways of disclosing, and... the testing bit was interesting as well, (...) that's the kind of stuff I think I'll revisit sooner rather than later." [P6]

"I think there was one about sort of testing it out with somebody about what their views are on mental health or something. And I didn't do that because that just felt really unnecessary... yeah, and a bit forced in a way (...)." [P27]

For some, the intervention was a support in managing mental health difficulties in the workplace.

"It did actually as I had a bit of a relapse of my difficulties during the intervention and I found the tools and workbooks helpful to navigate that while at work." [P8]

"I actually about three or four weeks ago ended up taking a week off, pretty much for stress, which I have never done before, erm... discussed it very openly with my manager who was so supportive, that I just thought 'Oh, okay, that was quite nice' (...) and I also in the midst of all this disclosed to a colleague about my own mental health history, erm... and I actually felt completely fine afterwards (...)." [P27]

However, the intervention did not necessarily alleviate feelings of distress and shame for everyone who decided to try disclosing.

"I did disclose after the intervention, to a colleague, but I have to be honest that I probably only did it to test the waters a bit and see if disclosing was actually as bad as I had imagined. I still felt ashamed and a little regretful and defective, but I'd say that the workbook did at least make me start thinking about my need to have conversations with people about my experiences." [P48]

A few participants also commented on barriers and difficulties, in addition to the length of the intervention mentioned previously, that could potentially reduce the effectiveness or accessibility of the intervention.

"The forum can feel a bit overwhelming, especially if you join late. It would be nice if it had an Introductions sub-forum and if conversations could be split? At the moment it feels all disorganised to me." [P6]

"It was strange to complete this [intervention] and not talk about it with colleagues as the criteria for completing it was to have experienced MH problems, therefore to discuss was to reveal." [P19]

4. Adverse effects or risks:

No participants raised concerns that the intervention was harmful when asked about this directly.

"I don't think it was harmful. Like I said there were times where I wasn't quite maybe engaging with it so well because I wasn't... I don't know, maybe not in the right place but that's not because of the guide if that makes sense, and it wasn't harmful I don't think, no." [P6]

One participant shared that the intervention elicited some feelings of guilt as they wanted to disclose more openly in order to tackle public stigma but did not feel ready to take that step.

"They made me feel slightly guilty, even though they are not setting out to do that, in that... I admire the courage and the bravery of the people who actively advocate and put themselves out there to say that they are dual status professionals. And in a way, part of me feels that I should, but part of me is too worried at this stage, when actually I think as a profession if we don't take courage being clinical psychologists then who else could we ask to be that courageous. (...) It's not a negative effect, it's just a reflection on my personal values and what I want to stand for." [P2]

Another participant commented that after an initial positive disclosure experience, they started to feel less in control of what they might inadvertently disclose.

"I think there is a bit of me that at one point just started feeling really uncontained, and I think... and that led to me actually thinking "Well, I need to ask for a week off" ... because I just thought "Oh my gosh, I might just end up telling everybody everything about me" (...)." [P27]

When asked what they attributed this to, they ascribed the sense of feeling uncontained to a mixture of the stressful situation they were in and completing the self-help guide.

Some participants commented in the SAT questionnaire that the outcome measures brought up negative emotions for them:

"Some [measures] raised some uncomfortable feelings but this was manageable." [P11]

"I felt that it was too personal, as if the problems were internalised stigma and discrimination rather than real life experience of this." (P34)

"I felt I was judged as prejudiced or discriminatory by terminology such as 'people are to blame for their problems'. [Because] I do think that people have a responsibility to themselves to recover, and to carry on regardless." [P34]

Finally, two participants commented on periods of low level of activity in the peer forum during which some posts were left without acknowledgment or response which may have negatively impacted upon the original poster:

"The only bit of it that sort of worried me a little bit, that I know I contributed to this as well, was that if somebody wrote something that was sort of quite detailed and in depth and insightful and personal, and then nobody commented on it for like a few days or a week. I just thought "Oh gosh, what has this person been left with?" [P27]

"The peer forum was very quiet with long gaps between replies (I know this is out of control of the research team), but it actually ended up feeling a bit uncomfortable." [P5]

5. Adherence.

The overall attrition rate was 19.6%, based on a dropout figure of '10' between baseline and T1 which is similar to the dropout rate in Rüsch et al. (2014). The ten participants who were still in progress were also participants who had been recruited more recently. The attrition rate was 30.8% for the intervention arm (eight participants

marked as dropouts, five still in progress) and 8% for the control arm (two participants marked as dropouts, five still in progress). The higher dropout rate in the intervention arm might link to some participants' concerns around acceptability highlighted above regarding the length and time taken to complete both the guide and the surveys, whereas control participants might have been more motivated to progress through the surveys in order to receive a copy of the guide.

Most participants took longer than anticipated to complete the self-help guide and it is not possible to determine based on data from this trial whether most participants spent the recommended amount of time on each session. However, the feedback from the telephone interviews suggests that participants varied significantly in the amount of time they dedicated to the sessions and worksheets and how they fitted the intervention around their usual routines. In addition, the available data indicated that participants are likely to have selected to complete only those parts of the guide that seemed relevant to them, so each participant might have followed a slightly different structure.

6. Additional feedback regarding acceptability of the peer forum.

The peer forum appeared to be one of the most valued and helpful components of the intervention as it provided a space to share one's thoughts about the worksheets and connect with people who had similar experiences as dual status professionals which was validating and de-shaming:

"I got much more out of the forum, and I had already done all of the exercises by then, but actually talking through them really really helped. (...) People sort of shared my experience to an extent, others didn't quite, but it's just helpful to see what others think."

[P6]

"Just being in a space where other people talked really openly about their own experiences and the impact on them now (...) I mean for me, I sort of never really had these conversations with people... and I think I actually took more from that than the rest of it (...)." [P27]

Anonymity was crucial to participants, and concerns over the anonymity of the forum were a potential barrier to participation:

"I think that helped, I mean the kind of anonymity, like just really being able to put things out there without anybody knowing who you are was... yeah..." [P27]

"I have never used an online forum and also worried that it wouldn't be anonymous."
[P19]

Some participants also struggled with anxiety about making an initial post or had made limited contributions to the discussion; however, just reading other people's post still benefited some people.

"I sort of sat back for a few days and read through what other people had written and then it did feel quite scary... in terms of writing something." [P27]

"I mostly lurked, I didn't engage in that much discussion but it was good to see what other people were talking about and to make the occasional comment. And I think that itself is an intervention because it reduces my isolation." [P2]

"I enjoyed that I could complete it at my own pace, and had access to the peer forum if difficulties came up throughout the intervention but there was no pressure to post in there if I didn't want to." [P8]

For further sub-themes of participants' comments regarding the benefits of the peer forum and suggestions for improvements (e.g. regarding the design or layout of the forum) please refer to Appendix I.

Quantitative data.

Only results from the ITT analysis are described in this section and presented in Table 2 below. Results from the analysis of the original (non-ITT) data are presented in a table in Appendix J.

Normality testing.

All outcome data were tested for normality of the distributions of mean scores for each group using skewness and kurtosis z-scores as recommended by Field (2013) for small samples (n < 50). If absolute z-scores were larger than 1.96 (p = 0.05) this indicated a significant departure from normality (Field, 2013). Histograms were also used as a visual means of checking the distribution but were attributed less importance as they are less accurate for small samples. Data were tested for outliers using boxplots and standardised z-scores, with potential outliers denoted by z-scores >1.96 (around 5% or less of these are expected in a normal distribution), probable outliers by scores >2.58 (around 1% or less of these are expected in a normal distribution) and extreme outliers by z-scores > 3.29 of which none should be present in a normal distribution (Field, 2013). All extreme outliers were corrected using 'Winsorizing' in which an outlier is substituted with the nearest non-outlier value (Field, 2013), and other potential and probable outliers were corrected with the same method if they were above the expected percentages for a normal distribution. All skewness and kurtosis values were within the normal range once outliers had been corrected. All data met essential assumptions for a mixed design ANOVA (Field, 2013).

Stigma Stress.

Mean scores (Table 2) were below zero for both groups at baseline, indicating that participants perceived their resources to cope with stigma as greater than the perceived threat or harm of stigma. Mean scores for both groups decreased a little further between baseline and T1, more so in the control group than intervention group; however, there was no significant difference between conditions (p = .395) or timepoints (p = .260). The ITT analysis revealed a small effect size of d = 0.204 for the primary outcome of Stigma Stress, with F(1, 39) = 0.41, p = .527 for the interaction effect between time-point and condition.

Secondary outcomes.

Secrecy. Mean scores on the secrecy scale were low for both groups at baseline indicating that participants on average 'disagreed' with the need to conceal

one's mental health problem. There was a medium effect size on Secrecy Scale (*d* = 0.542), with intervention group scores decreasing further, indicating stronger disagreement with the need for secrecy, whilst control group scores slightly increased.

Likelihood of Disclosure. Baseline mean scores on four subscales of the 'DOLE – past mental health problems' measure indicated that on average intervention group participants were 'undecided' about the likelihood of disclosing a past mental health problem to their Social Network or a Healthcare Professional, and thought that disclosure to their Professional Network or Clients was 'somewhat unlikely'. Controls were on average undecided on the Social and Professional Network subscales, rated disclosure to Clients as 'somewhat unlikely' and rated disclosure to a Healthcare Professional as 'likely' at baseline. A very large, significant effect (d = 1.893) was found on the Healthcare Professional subscale of this measure, as likelihood of disclosure notably decreased in the control group whilst intervention group scores remained constant, with F(1,15)=13.02, p = 0.003 for the interaction effect. There was also medium effect on the Clients subscale of this measure (d = 0.522), as likelihood of disclosure increased slightly in the intervention group but not in the control group.

Baseline mean scores on the four subscales of the 'DOLE – *present* mental health problems' measure generally followed a similar pattern to the previous DOLE measure. Effect sizes for the four subscales of this were small and there appeared to be little change over time, although the general trend appeared to be a lower likelihood of disclosure over time. Participants' usage pattern of the response option 'I've already disclosed to them' indicated that the intended use for this option was misinterpreted and the results for it were therefore unreliable and difficult to interpret, so they are not presented here.

Disclosure-related Distress. Baseline mean scores on all four subscales of the 'Disclosure Distress – Being Found Out' measure indicated that participants in both groups were on average 'a little' to 'moderately' distressed or worried about others finding out about their mental health problem. There was a significant, medium to large effect on the Professional Network subscale of this measure (d = 0.753), with

intervention participants' distress decreasing and control group participants' distress increasing between time-points, with F(1,37) = 5.24, p = .028 for the interaction effect. There were small effects on the remaining three subscales, with mean scores in both groups decreasing slightly between time-points on the Social Network and Healthcare Professionals subscales (i.e. small decreases in worry or distress) and increasing slightly on the Clients subscale.

Baseline mean scores on the four subscales of the 'Disclosure Distress – Keeping it secret' measure indicated that participants in the intervention group were on average 'a little' to 'moderately' distressed or worried about others finding out about their mental health problem, whilst controls were 'somewhat' to 'moderately' distressed or worried. There was a medium effect on the Professional Network subscale of the 'Disclosure Distress - Keeping it secret' measure (d = 0.502), with distress and worry scores increasing slightly in the intervention group whilst decreasing in the control group. There were small effects on the remaining three subscales of this measure with distress and worry decreasing slightly in both groups between time-points.

Perceived benefits and experiences of disclosure. Baseline mean scores on the COMIS indicated that both groups were on average undecided about the benefits of disclosure and 'somewhat agreed' with the reasons for concealment. Effect sizes for both subscales were small and there was little change between the two time-points.

Mean scores indicated a very small increase in agreement with benefits of disclosure in the intervention group and a slight decrease in agreement with the reasons for concealment in both groups. There was little change in the extent of disclosure between the two time-points. At T0, 7 participants in the intervention group and 9 participants in the control group reported having disclosed to most of their social network (whilst 14 and 11 participants respectively reported not having disclosed widely). At T1, there was no change in the intervention group whilst only 8 people in the control group reported having disclosed to most of their social network.

Table 2

Means (SDs) and statistics for ITT ANOVAs

Outcome measures	Mean (<i>SD</i>) at T0	Mean (<i>SD</i>) at T1	F-statistic (interaction)	<i>p</i> -value	Cohen's d
Stigma Stress Intervention (n = 21)	-0.95 (1.55)	-0.98 (1.41)	0.41	.527	0.204
Control $(n = 20)$	-0.44 (1.85)	-0.71 (1.51)			
Secrecy Scale Intervention (n = 21)	2.17 (0.45)	2.05 (0.49)	2.87	.098	0.542
Control $(n = 20)$	2.26 (0.49)	2.29 (0.49)	2.07	.000	0.0.2
<u>Disclosure Distress –</u> <u>Being Found Out</u> :					
Social Network Intervention (n = 19)	3.02 (1.67)	2.89 (1.83)	0.51	.478	0.242
Control $(n = 18)$	3.73 (1.35)	3.32 (1.41)			
Professional Network	4 22 (4 27)	0.70 (4.04)			
Intervention $(n = 19)$ Control $(n = 20)$	4.28 (1.97) 4.05 (1.56)	3.59 (1.94) 4.22 (1.61)	5.24	.028	0.753
Healthcare					
Professionals	2.47 (1.60)	2.27 (1.53)	0.94	.343	0.40
Intervention $(n = 15)$ Control $(n = 11)$	2.64 (1.75)	2.00 (1.10)			
Clients	2.20 (4.74)	2.50 (2.20)	4.04	224	0.224
Intervention $(n = 20)$ Control $(n = 19)$	3.26 (1.74) 4.03 (1.27)	3.50 (2.26) 4.80 (1.65)	1.01	.321	0.331
<u>Disclosure Distress –</u> <u>Keeping it secret</u> :					
Social Network	3.67 (1.90)	2.77 (1.30)	0.29	.592	0.173
Intervention $(n = 21)$ Control $(n = 20)$	3.87 (1.76)	2.70 (1.23)	0.20	.00_	00
Professional Network					
Intervention $(n = 20)$ Control $(n = 20)$	3.10 (1.61) 4.11 (1.44)	3.25 (1.50) 3.64 (1.17)	2.39	.130	0.502
Healthcare					
Professionals	2.27 (1.28)	2.27 (1.33)	0.60	.449	0.34
Intervention $(n = 15)$ Control $(n = 9)$	3.44 (1.42)	2.89 (1.54)			
Clients					
Intervention $(n = 20)$ Control $(n = 19)$	3.75 (1.94) 3.74 (1.53)	3.00 (1.88) 3.55 (2.15)	0.55	.462	0.244

Table 2 (continued)

Outcome measures	Mean (<i>SD</i>) at T0	Mean (<i>SD</i>) at T1	F-statistic (interaction)	<i>p</i> -value	Cohen's
DOLE – past					
Social Network					
Intervention $(n = 20)$	3.73 (1.49)	3.73 (1.26)	0.81	.373	0.296
Control $(n = 19)$	3.73 (1.49)	3.60 (1.44)	0.01	.373	0.290
,	3.90 (1.30)	3.00 (1.44)			
Professional Network					
Intervention $(n = 20)$	3.39 (1.40)	3.43 (1.28)	1.55	.221	0.409
Control $(n = 19)$	4.31 (1.15)	3.93 (1.37)			
l loolthaara					
Healthcare Professionals	4.00 (4.76)	4.00 (4.40)	13.02	.003	1.893
	4.00 (1.76)	4.00 (1.49)	13.02	.003	1.093
Intervention $(n = 10)$	5.71 (0.76)	4.14 (1.86)			
Control $(n = 7)$					
Clients					
Intervention $(n = 20)$	2.58 (0.94)	2.93 (1.31)	2.59	.116	0.522
Control $(n = 20)$	2.95 (1.45)	2.90 (1.42)			
, ,	, ,	, ,			
DOLE – present					
Social Network					
Intervention $(n = 19)$	4.13 (1.29)	3.28 (1.67)	0.73	.398	0.285
Control (<i>n</i> = 19)	4.11 (1.69)	3.69 (1.97)			
Professional Network					
Intervention $(n = 19)$	3.46 (1.46)	3.41 (1.67)	0.02	.893	0.045
Control (n = 19)	4.16 (1.17)	4.05 (1.47)			
Healthcare					
Professionals	4.93 (1.98)	3.46 (1.82)	0.62	.438	0.292
Intervention $(n = 15)$	5.63 (0.96)	4.70 (1.86)	0.02	. 100	0.202
Control $(n = 16)$	0.00 (0.00)	5 (1.05)			
Clients					
Intervention $(n = 15)$	1.93 (0.94)	1.93 (1.08)	0.21	.653	0.164
Control $(n = 18)$	2.36 (1.19)	2.58 (1.31)			
COMIS					
COMIS					
Benefits of Being Out	3 00 (0 96)	4.04.(0.07)	0.40	670	0.420
Intervention $(n = 21)$	3.99 (0.86)	4.04 (0.97)	0.18	.673	0.136
Control $(n = 20)$	4.49 (0.94)	4.47 (0.62)			
Doggoon for Oter in a 1					
Reasons for Staying In	E 07 (4 00)	E 04 (0.00)	1.00	202	0.005
Intervention $(n = 21)$	5.07 (1.08)	5.04 (0.68)	1.09	.303	0.335
Control $(n = 20)$	5.45 (0.85)	5.21 (0.91)			
Extent of Disclosure					
Intervention $(n = 21)$	1.67 (0.48)	1.67 (0.48)	0.14	.707	0.122
Control $(n = 20)$	1.55 (0.51)	1.60 (0.50)			

Discussion

This was the first study trialling a self-help intervention for disclosure-related decisions with a sample of mental health professionals in the UK. The study set out to develop an intervention that was acceptable and feasible for use with this population and to examine preliminary outcomes regarding the efficacy of the intervention on a range of outcomes relating to stigma, disclosure and distress. The acceptability of the intervention was generally high, and a majority of participants reported finding it at least somewhat helpful. Nevertheless, participants made several suggestions for improving the acceptability of the intervention and outcome measures.

The intervention showed medium to large effects in terms of reductions of distress or concern about being found out by others in one's professional networks and the perceived need or importance of secrecy. However, most of the outcomes differed from the expected results. Contrary to predictions, the intervention had only small effects on stigma stress and perceived benefits of disclosure. In addition, there was little change in actual disclosure and likelihood of disclosure of current mental health difficulties, although the intervention resulted in a medium to large increase in likelihood of disclosure of past mental health problems. Results, implications for research, policy and practice, and limitations of the study are discussed in more detail below.

Acceptability of the intervention and outcome measures

Overall, the acceptability of the intervention was high and participants described benefiting from parts of the self-help guide and from the peer forum. The latter in particular seemed valued by most participants, and the three who took part in telephone interviews described how the forum eventually became more helpful and impactful than the self-help guide. At T1, over 90% of the 13 satisfaction survey respondents described the intervention as helpful and indicated they would recommend it to others, although these figures had decreased to 80% and 60% respectively at T2 when there were only five respondents. There was some disagreement over which parts of the guide were more or less helpful, with two of the interviewees suggesting that their existing professional skills made the section on testing out whether a person might be suitable

for disclosure feel unnecessary, whilst the third interviewee said they wanted to revisit that section in the future as it would be helpful for them.

Based on the satisfaction data, several participants felt that the self-help guide was quite lengthy and time intensive, and difficult to fit around existing work commitments. It is possible that this caused some participants to procrastinate getting started with the guide and could explain why participants took longer than expected to complete the core sessions, and why two (40%) of the five SAT respondents at T2 were undecided whether they would recommend the intervention to others. Similarly, whilst several participants experienced the outcome measures as sensitive, thoughtful and an opportunity to reflect, there was frequent feedback that they were lengthy and somewhat repetitive, and that some questions were too ambiguous.

In addition, one participant who struggled with personal stressors during the intervention and had previously never felt able to disclose to anyone in their professional circle, decided to disclose to their manager and a colleague during the intervention. They commented that whilst these disclosures had positive outcomes, they began to feel "uncontained" afterwards and concerned that they may lose control and unintentionally disclose to everyone around them. This indicates that the intervention could feel overwhelming for some people during stressful times, and it could be helpful to acknowledge this in the preface.

Preliminary outcomes

Stigma Stress. In both the control and intervention groups, stigma stress appraisal scores reduced over time and there was no significant difference between them, indicating that both groups perceived stigma as slightly less harmful or threatening to them over time. These results differ from other trials which found significant improvements in stigma stress appraisals for those who had received the HOP intervention (Mulfinger et al., 2018; Rüsch et al., 2014). One possible reason for this is that baseline mean scores were already below zero at baseline and therefore indicative of overall healthy stigma stress appraisals. This could mean that there was limited scope for positive change. Alternatively, whilst participants may have felt they had the

resources to cope with stigma, reflecting on the pros and cons of disclosure as part of the intervention may have evoked images of situations where stigma could pose a threat to their personal and professional lives (Smart Richman & Leary, 2009), thereby keeping the difference between perceived coping resources and perceived harm of stigma fairly static.

Secrecy. Over time, participants in the intervention group agreed less strongly with the idea that concealing mental health problems is advisable whilst control group participants' agreement increased. This could be linked to a change in participants' perceptions of the pros and cons of disclosure after reflecting on this as part of the intervention. However, participants' agreement with secrecy was low to begin with as baseline mean scores for both groups indicated that they generally disagreed with the need for secrecy, so again the scope for further change in that direction was limited. Additionally, the majority of items on the secrecy scale are less personal than on the other measures as they ask participants to indicate what they would advise other people to do, so participants might rate these different in relation to themselves and their context.

Likelihood of Disclosure. Both groups' likelihood of disclosing a *current* mental health problem decreased over time which could be linked to some of the reasons discussed above in relation to increased worry or distress about keeping one's difficulties secret. However, those in the intervention group reported greater likelihood of disclosure of past lived experience to their professional network, healthcare professionals and clients following the intervention. This change was most pronounced for the Healthcare Professionals subscale, and indicates that mental health professionals might feel more comfortable telling their GP or other healthcare providers about mental health problems they experienced in the past. Perhaps participants perceived healthcare providers as responding more favourably to stories of past difficulties one has 'overcome' or recovered from, as opposed to current distress. There is some evidence in literature on other stigmatised identities that when seeking

healthcare, people may employ a 'persona' to please the healthcare professional (Campbell et al., 2015).

Disclosure Distress. Results indicated that intervention group participants' distress and concern about 'being found out' by their colleagues, peers, supervisors or managers significantly decreased over time. Participants in the intervention group had access to the peer forum which appeared to be quite eye-opening for several participants in terms of hearing other professionals' stories about their mental health problems. This was generally experienced as normalising, validating and supportive.

One could hypothesise that forum participation increased participants' expectations and awareness that at least some of their colleagues would have lived experience of mental health problems themselves, as research involving the general population has found that online peer support can reduce isolation and enhance one's perceived coping ability (Naslund, Grande, Aschbrenner & Elwyn, 2014), and that social media use can contribute to a sense of social connectedness (Grieve, Indian, Witteveen, Tolan & Marrington, 2013; Naslund, Aschbrenner, Marsch & Bartels, 2016). It is possible that a sense of shared lived experience with peers could lead to a reduction in worry that someone would respond negatively if they discovered one's personal difficulties.

It is worth noting that intervention group participants' distress and worry increased slightly in relation to keeping their mental health problem secret from their professional network (from being closer to 'a little' worried to being closer to 'somewhat worried'), whilst control group scores improved. One possibility is that discussion on the forum included sharing stories of times disclosure resulted in a negative or unhelpful response from the disclosure target (e.g. a colleague). In this way, the forum might function to both decrease distress and worry through the process of normalising whilst simultaneously increasing distress or worry about concealing one's difficulties or lived experience by making the possibility of a negative disclosure outcome more salient. Support for this hypothesis can be found in research looking at peer support in other populations; for example, people who have motor neurone disease and their carers reported that engaging in peer support can be normalising and provide hope but can

also be distressing and increase awareness of what may happen to them in the future (Locock & Brown, 2010). Alternatively, spending more time than usual reflecting on their lived experience and on potential negative reactions from others whilst completing the guide, in combination with having less peer support than participants in the original HOP intervention, may have contributed to the increase in distress and worry. Participant feedback also indicated that some participants felt unclear about the difference between the two Disclosure Distress Scales ('Being Found Out' versus 'Keeping your Mental Health Problem Secret') so it is possible that the scales did not measure what they were intended to measure.

Perceived Benefits of Disclosure (COMIS). Over time, intervention group participants showed slightly stronger agreement with potential benefits of disclosure and both groups showed slightly weaker agreement with reasons for concealment but there was no significant difference between either the groups or time points. Overall, both groups agreed more strongly with reasons for concealment compared to benefits of disclosure. In addition, there was no change in the extent of disclosure in the intervention group.

Implications and recommendations.

The findings describe a pattern whereby the intervention appears to have led to some improvements in participants' concerns that others might find out about their mental health difficulties, and also contributed to reducing participants' endorsement of the importance of secrecy. However, participants' agreement with the need for secrecy was low to begin with, and any actual increase in likelihood of disclosure seemed to only pertain to past but not present mental health problems. In this sample, which consisted predominantly of qualified and trainee clinical psychologists, stress and distress related to stigma, disclosure and secrecy was on average moderate to low at the outset. Most baseline mean scores on these measures were slightly higher in HOP trials that were not focused on mental health professionals (Mulfinger et al., 2018; Rüsch et al., 2014). This could be a result of self-selection bias in this sample, in that perhaps those mental health professionals with a pre-existing interest and positive attitude towards disclosure

signed up to participate in this study, whereas those who might have scored higher on measures of secrecy, stigma stress and disclosure-related distress were less likely to volunteer for this study.

Lower levels of stress and distress relating to concealment may also explain why there was less change in likelihood of disclosure and perceived benefits of disclosure, as a large proportion of participants might not have felt they needed to seek additional support. Almost all participants indicated that they had sought professional help for their mental health problems (Table 1) which could also account for these findings. It is also possible that participants more strongly agreed with reasons for disclosure which were not explicitly measured in this study, such as helping to shift public stigma. One implication is that the measures chosen to assess change or improvements in this sample might not quite tap into the key benefits participants described in the qualitative data. These seemed to be more around having the opportunity to reflect on one's experiences and beliefs, being able to exchange stories with others and thereby feeling less isolated.

Another implication is that self-help interventions in this area may not be comparable to face-to-face interventions in terms of the expected timeframe for change to occur (de Zwaan et al., 2017). For example, it appeared that at least some participants completed some parts of the guide first, revisited some parts later and decided to save other parts for the future when they would feel readier to tackle them. In comparison, in a group setting facilitators and peers may provide the containment and immediate support to help everyone complete each session as intended and spend time processing their thoughts and reflections through discussion. In contrast, it appeared that discussion on the peer forum moved at a slower pace and posts were sometimes not responded to for several days. As a result, participants might have taken longer to process and feel comfortable with new ideas.

Future research should look into whether these patterns are replicated with larger and more diverse samples of mental health professionals. It would be beneficial to conduct further interviews and expand the satisfaction questionnaire to gain further

insight into the benefits mental health professionals draw from this intervention and how these might best be measured quantitatively. Future studies testing this intervention should also address the concerns raised by participants regarding the length, repetitiveness and ambiguity of some of the outcome measures. Additionally, it might help to pre-empt procrastination by recommending that participants skim read the guide first to get an idea of how long each session might take to complete and identify which parts they might want to spend more time on.

As the peer support forum was described as valuable and helpful by participants, mental health professionals might benefit from being able to access safe and meaningful peer support spaces within their organisations. If this was in the form of a web-based forum, feedback from this study indicated that it would be helpful to have more active peer moderators on the forum and to make sure that all posts are acknowledged and responded to.

Limitations.

Although more participants signed up to participate in the study than the minimum calculated in the power analysis, sample size became a significant limitation in terms of the number of participants progressing to the second and third time points. The low sample size in the intervention group at T1 (13 participants) was unlikely to provide enough power to detect significant differences between groups. The use of ITT analysis caused the mean scores at T1 to potentially be more conservative than they may have been if more participants had completed the survey as qualitative data indicated that the main barriers were time intensiveness of the intervention and measures, although it is possible that those who did not progress to T1 had other reasons for withdrawing that they did not share with the research team.

Due to recruitment difficulties discussed earlier, qualified psychologists were only reached via select routes. Outcomes may not have been representative of the impact of the intervention due to variable suitability of the measures chosen for the study. Some of the measures appeared to cause confusion for participants in terms of

what specifically they were asking, and the measures as a whole appeared to only partly capture participants' goals and perceived benefits of the intervention.

A low amount of quantitative data at T2 meant that it was not possible to assess whether initial changes are maintained or additional changes potentially detected after a longer follow-up period, during which participants would have had more time to reflect and process new ideas. Additionally, the low amount of qualitative data at T2 means that the high satisfaction and helpfulness ratings may not be representative of the sample as a whole as it is likely that the five intervention participants who provided satisfaction data at T2 benefitted most from the intervention.

Two of the outcome measures ('Disclosure of Lived Experience' and 'Disclosure-related distress') used in this study lacked information regarding their psychometric properties. Therefore, it was not possible to establish whether they achieved satisfactory reliability or validity. This limits the conclusions that can be drawn from the data collected by those measures as it cannot be determined whether they are appropriate instruments for measuring the outcomes this intervention intended to measure.

Finally, whilst the peer forum seemed most highly praised out of the different parts of the intervention, it was not possible to evaluate the differential impact of the different intervention components (e.g. different sessions of the guide, peer forum, website resources) based on the available data, and it was unclear whether resources like the study website were seen as helpful by either group.

Conclusion.

In general, the results indicate that whilst acceptability was high and participants rated the intervention as helpful, quantitative showed only limited benefits of the intervention. Further, some aspects of the intervention reduced acceptability and thereby formed obstacles to participation and completion of the intervention. If these were addressed, this might also increase the feasibility of conducting a trial with a larger number of participants and retaining more participants for the duration of the trial.

References

- Brohan, E., Henderson, C., Wheat, K., Malcolm, E., Clement, S., Barley, E. A., ...

 Thornicroft, G. (2012). Systematic review of beliefs, behaviours and influencing factors associated with disclosure of a mental health problem in the workplace.

 BMC Psychiatry, 12. https://doi.org/10.1186/1471-244X-12-11
- Campbell, C., Scott, K., Skovdal, M., Madanhire, C., Nyamukapa, C., & Gregson, S. (2015). A good patient? How notions of 'a good patient' affect patient-nurse relationships and ART adherence in Zimbabwe. *BMC Infectious Diseases, 15*, 404-414. https://doi.org/10.1186/s12879-015-1139-x
- Centers for Disease Control and Prevention. (2006). *Gaining Consensus Among Stakeholders Through the Nominal Group Technique*. Retrieved from https://www.cdc.gov/healthyyouth/evaluation/pdf/brief7.pdf
- Christensen, H., Griffiths, K. M., & Jorm, A. F. (2004). Delivering interventions for depression by using the internet: randomised controlled trial. *BMJ*, 328, 265. https://doi.org/10.1136/bmj.37945.566632.EE
- Corrigan, P. W., & Bink, A. B. (2016). The Stigma of Mental Illness. *Encyclopedia of Mental Health*, *4*, 230–234. https://doi.org/10.1016/B978-0-12-397045-9.00170-1
- Corrigan, P. W., Kosyluk, K. A., & Rüsch, N. (2013). Reducing self-stigma by coming out proud. *American Journal of Public Health*, *103*, 794–800. https://doi.org/10.2105/AJPH.2012.301037
- Corrigan, P. W., Larson, J. E., Michaels, P. J., Buchholz, B. A., Rossi, R. Del, Fontecchio, M. J., ... Rüsch, N. (2015). Diminishing the self-stigma of mental illness by coming out proud. *Psychiatry Research*, 229, 148–154. https://doi.org/10.1016/j.psychres.2015.07.053
- Corrigan, P. W., Morris, S., Larson, J., Rafacz, J., Wassel, A., Michaels, P., ... Rüsch, N. (2010). Self-stigma and coming out about one's mental illness. *Journal of Community Psychology*, 38, 259–275. https://doi.org/10.1002/jcop.20363

- Craig, P., Dieppe, P., Macintyre, S., Michie, S., Nazareth, I., & Petticrew, M. (2006).

 Developing and evaluating complex interventions: new guidance. London, UK:

 Medical Research Council. Retrieved from

 www.mrc.ac.uk/complexinterventionsguidance
- Crisp, A. H., Gelder, M. G., Rix, S., Meltzer, H. I., & Rowlands, O. J. (2000).

 Stigmatisation of people with mental illnesses. *British Journal of Psychiatry*, 177, 4–7. https://doi.org/10.1192/bjp.177.1.4
- Dawson, J. (2014). Staff Experience and Patient Outcomes: What do we know?

 Retrieved from https://www.nhsemployers.org//media/Employers/Publications/Research-report-Staff-experience-and-patientoutcomes.pdf
- de Zwaan, M., Herpertz, S., Zipfel, S., Svaldi, J., Friederich, H., Schmidt, F., ... Hilbert, A. (2017). Effect of Internet-Based Guided Self-help vs Individual Face-to-Face Treatment on Full or Subsyndromal Binge Eating Disorder in Overweight or Obese Patients: The INTERBED Randomized Clinical Trial. *JAMA Psychiatry*, 74, 987–995. https://doi.org/10.1001/jamapsychiatry.2017.2150
- Dinos, S., Stevens, S., Serfaty, M., Weich, S., & King, M. (2004). Stigma: the feelings and experiences of 46 people with mental illness. *British Journal of Psychiatry*, 184, 176–181. https://doi.org/10.1192/bjp.184.2.176
- Disability Rights UK. (2014). The Potential for Attitude and Behaviour Change Driven by

 Mental Health Professionals: A Scoping Report for Time to Change. Retrieved

 from https://www.time-to-change.org.uk/sites/default/files/Mental health

 professional scoping report.pdf
- Ellemers, N., & Barreto, M. (2006). Social identity and self-presentation at work: how attempts to hide a stigmatised identity affect emotional well-being, social inclusion and performance. *Netherlands Journal of Psychology*, *62*, 51–57. https://doi.org/https://doi.org/10.1007/BF03061051

- Faul, F., Erdfelder, E., Lang, A.-G., & Buchner, A. (2007). G*Power 3: a flexible statistical power analysis program for the social, behavioral, and biomedical sciences. *Behavior Research Methods*, *39*, 175–191. https://doi.org/https://doi.org/10.3758/BF03193146
- Field, A. (2013). *Discovering Statistics Using IBM SPSS Statistics* (4th ed.). London: SAGE Publications Ltd.
- Garthwaite, K. (2016). Stigma, shame and "people like us": an ethnographic study of foodbank use in the UK. *Journal of Poverty and Social Justice*, *24*, 277–289. https://doi.org/10.1332/175982716X14721954314922
- Grice, T. (2016). Factors Affecting Disclosure of Mental Health Problems. (Unpublished doctoral dissertation). University College London, London, UK.
- Grice, T., Alcock, K., & Scior, K. (2018). Factors Associated With Mental Health Disclosure Outside of the Workplace: A Systematic Literature Review. Stigma and Health, 3, 116-130. https://doi.org/10.1037/sah0000079
- Grieve, R., Indian, M., Witteveen, K., Tolan, G. A., & Marrington, J.(2013). Face-to-face or Facebook: Can social connectedness be derived online? *Computers in Human Behavior*, 29, 604-609. https://doi.org/10.1016/j.chb.2012.11.017
- Gupta, S. K. (2011). Intention-to-treat concept: A review. *Perspectives in Clinical Research*, 2, 109–112. https://doi.org/10.4103/2229-3485.83221
- Hansson, L., Jormfeldt, H., Svedberg, P., & Svensson, B. (2013). Mental health professionals' attitudes towards people with mental illness: Do they differ from attitudes held by people with mental illness? *International Journal of Social Psychiatry*, 59, 48–54. https://doi.org/10.1177/0020764011423176
- Henderson, C., Brohan, E., Clement, S., Williams, P., Lassman, F., Schauman, O., ...
 Thornicroft, G. (2012). A decision aid to assist decisions on disclosure of mental health status to an employer: Protocol for the CORAL exploratory randomised controlled trial. *BMC Psychiatry*, 12. https://doi.org/10.1186/1471-244X-12-133

- Henderson, C., Brohan, E., Clement, S., Williams, P., Lassman, F., Schauman, O., ...
 Thornicroft, G. (2013). Decision aid on disclosure of mental health status to an employer: Feasibility and outcomes of a randomised controlled trial. *British Journal of Psychiatry*, 203, 350–357. https://doi.org/10.1192/bjp.bp.113.128470
- Kleim, B., Vauth, R., Adam, G., Stieglitz, R.-D., Hayward, P., & Corrigan, P. (2008).
 Perceived stigma predicts low self-efficacy and poor coping in schizophrenia.
 Journal of Mental Health, 17, 482–491.
 https://doi.org/10.1080/09638230701506283
- Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). The PHQ-9: validity of a brief depression severity measure. *Journal of General Internal Medicine*, 16, 606–613. https://doi.org/10.1046/J.1525-1497.2001.016009606.X
- Krupa, T., Kirsh, B., Cockburn, L., & Gewurtz, R. (2009). Understanding the stigma of mental illness in employment. Work, 33, 413–425. https://doi.org/10.3233/WOR-2009-0890
- Lewis, C., Pearce, J., & Bisson, J. I. (2012). Efficacy, cost-effectiveness and acceptability of self-help interventions for anxiety disorders: systematic review. *British Journal of Psychiatry*, 200, 15–21. https://doi.org/10.1192/bjp.bp.110.084756
- Link, B. G., Struening, E. L., Neese-todd, S., Asmussen, S., & Phelan, J. C. (2002). On Describing and Seeking to Change the Experience of Stigma. *Psychiatric Rehabilitation Skills*, 6, 201–231. https://doi.org/10.1080/10973430208408433
- Locock, L., & Brown, J. B. (2010). 'All in the same boat'? Patient and carer attitudes to peer support and social comparison in Motor Neurone Disease (MND). Social Science & Medicine, 71, 1498-1505.

 https://doi.org/10.1016/j.socscimed.2010.06.043
- McMillan, S. S., King, M., & Tully, M. P. (2016). How to use the nominal group and Delphi techniques. *International Journal of Clinical Pharmacy*, *38*, 655–662. https://doi.org/10.1007/s11096-016-0257-x

- Moher, D., Hopewell, S., Schulz, K. F., Montori, V., Gøtzsche, P. C., Devereaux, P. J.,
 ... Altman, D. G. (2010). CONSORT 2010 explanation and elaboration: updated
 guidelines for reporting parallel group randomised trials. *BMJ*, *340*, c869.
 https://doi.org/10.1136/BMJ.C869
- Moore, G., Audrey, S., Barker, M., Bond, L., Bonell, C., Hardeman, W., ... Baird, J. (2015). Process evaluation of complex interventions. Medical Research Council guidance. *BMJ*, 350, h1258. https://doi.org/10.1136/bmj.h1258
- Mulfinger, N., Müller, S., Böge, I., Sakar, V., Corrigan, P. W., Evans-Lacko, S., ...

 Rüsch, N. (2018). Honest, Open, Proud for adolescents with mental illness: pilot randomized controlled trial. *Journal of Child Psychology and Psychiatry*, *59*, 684–691. https://doi.org/10.1111/jcpp.12853
- Naslund, J. A., Aschbrenner, K. A., Marsch, L. A., & Bartels, S. J. (2016). The future of mental health care: peer-to-peer support and social media. *Epidemiology and Psychiatric Sciences*, 25, 113–122. doi:10.1017/S2045796015001067
- Naslund, J. A, Grande, S. W., Aschbrenner, K. A., & Elwyn, G. (2014). Naturally Occurring Peer Support through Social Media: The Experiences of Individuals with Severe Mental Illness Using YouTube. *PLoS ONE*, 9, e110171. https://doi.org/10.1371/journal.pone.0110171
- Newheiser, A. K., Barreto, M., & Tiemersma, J. (2017). People Like Me Don't Belong

 Here: Identity Concealment is Associated with Negative Workplace Experiences.

 Journal of Social Issues, 73, 341–358. https://doi.org/10.1111/josi.12220
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, *133*, 328–345. https://doi.org/10.1037/0033-2909.133.2.328
- Quinn, D. M., & Chaudoir, S. R. (2009). Living With a Concealable Stigmatized Identity: The Impact of Anticipated Stigma, Centrality, Salience, and Cultural Stigma on Psychological Distress and Health. *Journal of Personality and Social Psychology*, 97, 634–651. https://doi.org/10.1037/a0015815

- Ragins, B. R., Singh, R., & Cornwell, J. M. (2007). Making the Invisible Visible: Fear and Disclosure of Sexual Orientation at Work. *Journal of Applied Psychology*, 92, 1103–1118. https://doi.org/10.1037/0021-9010.92.4.1103
- Rao, A. S., Bhutani, G., Dosanjh, N., Clarke, J., Hughes, J. H., Easton, S., ... Cohen-Tovée, E. (2016). *Psychological Wellbeing and Resilience: Resetting the Balance*. Retrieved from https://www1.bps.org.uk/system/files/Public files/ar_v10_resetting_the_balance_160516.docx.pdf
- Richards, D., & Timulak, L. (2013). Satisfaction with therapist-delivered vs. self-administered online cognitive behavioural treatments for depression symptoms in college students. *British Journal of Guidance & Counselling*, *41*, 193–207. https://doi.org/10.1080/03069885.2012.726347
- Richards, J., Holttum, S., & Springham, N. (2016). How Do "Mental Health Professionals" Who Are Also or Have Been "Mental Health Service Users" Construct Their Identities? *SAGE Open*, *6*, 1–14. https://doi.org/10.1177/2158244015621348
- Royal College of Physicians. (2015). Work and wellbeing in the NHS: why staff health matters to patient care. London, UK. Retrieved from https://www.rcplondon.ac.uk/file/2025/download?token=ebh7iiqv
- Rüsch, N., Abbruzzese, E., Hagedorn, E., Hartenhauer, D., Kaufmann, I., Curschellas, J., ... Corrigan, P. W. (2014). Efficacy of coming out proud to reduce stigma's impact among people with mental illness: Pilot randomised controlled trial.

 British Journal of Psychiatry, 204, 391–397.

 https://doi.org/10.1192/bjp.bp.113.135772
- Rüsch, N., Corrigan, P. W., Powell, K., Rajah, A., Olschewski, M., Wilkniss, S., & Batia, K. (2009). A stress-coping model of mental illness stigma: II. Emotional stress responses, coping behavior and outcome. *Schizophrenia Research*, *110*, 65–71. https://doi.org/10.1016/j.schres.2009.01.005

- Rüsch, N., Corrigan, P. W., Wassel, A., Michaels, P., Olschewski, M., Wilkniss, S., & Batia, K. (2009). A stress-coping model of mental illness stigma: I. Predictors of cognitive stress appraisal. *Schizophrenia Research*, *110*, 59–64. https://doi.org/10.1016/j.schres.2009.01.006
- Schulze, B. & Angermeyer, M. C. (2003). Subjective experiences of stigma. A focus group study of schizophrenic patients, their relatives and mental health professionals. *Social Science & Medicine*, *56*, 299-312.
- Sethi, S., Campbell, A. J., & Ellis, L. A. (2010). The Use of Computerized Self-Help

 Packages to Treat Adolescent Depression and Anxiety. *Journal of Technology in Human Services*, 28, 144–160. https://doi.org/10.1080/15228835.2010.508317
- Shaw Trust. (2018). *Mental Health at Work: Still the Last Taboo*. Retrieved from https://www.shaw-trust.org.uk/en-GB/Media-policy/Mental-Health-at-Work
- Sidani, S., & Braden, C. J. (2011). *Design, Evaluation, and Translation of Nursing Interventions*. Chichester, West Sussex: John Wiley & Sons, Inc.
- Smart Richman, L., & Leary, M. R. (2009). Reactions to discrimination, stigmatization, ostracism, and other forms of interpersonal rejection: a multimotive model. *Psychological review*, *116*, 365-383. https://doi.org/10.1037/a0015250
- Smith, R., Rossetto, K., & Peterson, B. L. (2008). A meta-analysis of disclosure of one's HIV-positive status, stigma and social support. *AIDS Care*, *20*, 1266–1275. https://doi.org/10.1080/09540120801926977
- Tay, S. (2016). Lived Experience of Mental Health Problems among Clinical
 Psychologists, Stigma and its Impact on Disclosure and Help-seeking.

 (Unpublished doctoral dissertation). University College London, London, UK.
- The British Psychological Society and New Savoy Conference. (2016). *Charter for psychological staff wellbeing and resilience*. Retrieved from https://www.healthcareconferencesuk.co.uk/news/newsfiles/charter-2016_1314.pdf

- Wahl, O. F. (1999). Mental Health Consumers' Experience of Stigma. *Schizophrenia Bulletin*, 25, 467–478.
 - https://doi.org/https://doi.org/10.1093/oxfordjournals.schbul.a033394
- Weisz, B. M., Quinn, D. M., & Williams, M. K. (2015). Out and healthy: Being more "out" about a concealable stigmatized identity may boost the health benefits of social support. *Journal of Health Psychology*, 21, 2934–2943.

https://doi.org/10.1177/1359105315589392

Part 3: Critical Appraisal

Overview

This critical appraisal explores reflections and challenges that arose throughout this project and focuses on three different areas. Initially, personal values, beliefs and assumptions around disclosure and stigma are explored in terms of how they influenced my motivation to conduct this research and how, in turn, the research project influenced them over time. The second part of the appraisal comprises reflections and a critique of the research process, including the adaptation of the intervention, participant recruitment, data collection and data analysis, and expands on some of the limitations of the research. The final section offers a brief summary of the main learning points arising from the challenges encountered in the research process as well as some further reflections on the study findings and their implications.

Reflections on the personal impact of the research

Assumptions and beliefs around disclosure and stigma. Whilst the HOP-MHP intervention helps people carefully weigh up disclosure decisions and does not proclaim that disclosure will be beneficial and suitable for every individual, my personal stance prior to the project was that if, as a profession, clinical psychologists were more open about their lived experience of mental health problems, this would be helpful for several reasons:

- a) to role model to other colleagues that it is okay to share one's experiences more openly if one wishes to do so, whether this is to gain support or simply to connect with others who may have had similar experiences;
- b) to de-shame and de-stigmatise mental health problems, particularly with regards to stigmatising attitudes held by mental health professionals themselves. If, for example, clinical psychologists, who can be considered to represent a respected and high achieving profession, shared their own experiences of mental health problems, this might help to reduce some of the negative connotations and judgments associated with mental health problems (Corrigan, Morris, Michaels, Rafacz, & Rüsch, 2012) as well as the 'them and us' culture in mental health settings;
- c) to have a positive impact on clinical psychologists and other mental health

professionals themselves, for example by reducing isolation, worry and stress experienced as a result of feeling one has to conceal one's mental health problems or concerns about the potential consequences if others found out (Pachankis, 2007; Quinn & Chaudoir, 2009), and increasing help-seeking behaviour.

These were some of the reasons I felt intrigued by this project and was keen to contribute to its development. Whilst prior to the project I was already aware of the potential negative consequences of disclosure as some of the reasons people choose not to disclose (Brohan et al., 2012; Joyce, Hazelton, & McMillan, 2007; Joyce, McMillan, & Hazelton, 2009), developing the HOP-MHP guide and considering the study results prompted me to reflect on the idea that some people may not experience any worry and distress due to concealment and may feel content not sharing their experience of mental health problems with (most) other people in their lives. Some individuals may feel that keeping their professional identity separate from their 'lived experience identity' causes them less stress and distress than other disclosure choices. For example, our results showed that whilst only 9 participants in each group considered themselves to have widely disclosed amongst their family and friends at baseline (and this had hardly changed at T1), disclosure-related stress and distress was on average low to moderate in both groups. Additionally, the stigma stress scores indicated that overall participants felt well equipped to cope with mental health stigma and were therefore not as concerned by negative personal and professional implications of stigma as I expected.

On the other hand, the findings did reinforce my belief that having a safe space where one can share one's lived experiences with others can help people feel less isolated and ashamed through the normalising and validating nature of the discussions (Naslund, Grande, Aschbrenner & Elwyn, 2014; Norris & DeMarco, 2005). Some participants in this study spoke about seeking more support in the workplace, disclosing to colleagues or raising the topic of wellbeing in the workplace during a team meeting (Appendix I). As a result of this research project, I continue to consider disclosure to have many benefits on a personal, professional and even societal level but have a

greater understanding of the range of reasons people may choose not to disclose and therefore no longer view disclosure as the most desirable in the context of a suitable setting because some professionals may feel happier to keep their experiences private even in a warm, supportive, sympathetic setting.

The personal and public implications of being a researcher on this project. It seems a reasonable assumption that one selects a research project because of an intrinsic interest in the topic or because it is in some way personally meaningful. One implication of being a researcher for this study is that one may have experiences of mental health difficulties either personally or amongst family or friends. As doctoral theses are publicly accessible and most people in the training cohort are aware of each other's thesis topics, conducting a study such as this one could be seen as an indirect disclosure which is difficult for at least two reasons: firstly, disclosure should be a personal decision in each individual context or setting, with the discloser choosing what to share; secondly, indirect disclosure was not entirely consistent with my personal values of wanting the profession to be more open about their experiences and leading by example. This therefore led me to wonder whether in some way, despite the research being aimed at tackling stigma and disclosure distress, there were underlying concerns about being perceived as unprofessional, incompetent or other negative consequences for the project were the research team to openly embody dual status professionals. One learning point for fellow researchers with an interest in this area is to carefully consider how being associated with this type of research may influence one's own thoughts, feelings, hopes and concerns about how others may perceive oneself. Additionally, it is possible that concerns about other people's perceptions may have contributed to this area being under-researched.

Challenges in the research process

Adapting the intervention and managing workload. The adaptation of the original HOP manual and workbook into the HOP-MHP guide was a work and time intensive process which spanned several phases. The initial prediction was that the project would be more time consuming in its early stages with the expected advantage

of completing data collection sooner than other peers in our cohort. However, arranging the stakeholder day took several months in order to give potential stakeholders sufficient notice. The next step involved drafting two of the four HOP-MHP guide sessions (with my colleague drafting the other two) which were reviewed and further adapted by the project supervisors, and were then revised two more times based on feedback from stakeholders and small pilot participants. Additionally, time was set aside to create other materials such as the study website and the web survey which was designed and tested using Qualtrics software, and to receive training from UCL Information Services Division in order to be able to use the Data Safe Haven to securely store sensitive and confidential information. Overall, the first two phases of the project took longer than anticipated which resulted in recruitment beginning and ending later than planned. Throughout the pilot randomised controlled trial (RCT), maintaining weekly email contact with all participants who were progressing through the trial was an additional key task.

The project supervisors' decision to make this a joint trainee project and to be closely involved throughout the process made the workload and pressures manageable as it was possible to divide tasks fairly between us and draw on the supervisors' knowledge, skills and experience to anticipate and resolve difficulties. For example, when we encountered recruitment difficulties in our original recruitment strategy (outlined below), the project supervisors were able to utilise other professional networks to help disseminate project information such as the Group of Trainers in Clinical Psychology (GTiCP) academic and clinical tutor mailing lists. Effective communication, maintaining a close working relationship with all members of the research team, and receiving regular supervision from experienced researchers (Severinsson, 2015) were key elements in managing the research process.

Recruitment and data collection. The project encountered several obstacles around recruitment, from the above-mentioned reasons for a delay in starting the pilot RCT, to difficulties in disseminating study information to the target population. The latter was mainly because our original recruitment plan relied substantially on an agreement made with the British Psychological Society's Division of Clinical Psychology (DCP) that

they would disseminate our study information to all their members via their mailing list, as they had done in Tay's (2016) study. This was in addition to the DCP agreeing to provide funding for our study, and both of those agreements contributed to the decision for this project to go ahead. However, unfortunately the study information was not disseminated via the DCP mailing list, despite repeated requests, due to ongoing discussions between the BPS and UCL about the wording of the contract associated with the funding. Hence, we decided to broaden the inclusion criteria to 'mental health professionals' rather than only including clinical psychologists and to recruit using a variety of strategies mentioned in the method section of the empirical paper. Whilst we eventually recruited the number of participants we originally aimed for, the obstacles along the way meant that there was no room for extending the recruitment phase further in an attempt to allow those participants still in progress to complete the second survey (T1) in order to increase the data available for comparison to baseline. Similarly, a smoother recruitment process may have meant that we could have spent more time collecting data for the third time-point and get a better understanding of the acceptability and preliminary outcomes regarding the efficacy of the intervention over a longer period of time.

Study limitations.

Outcome measures. Some participants raised concerns about the outcome measures being too long, repetitive, confusing, and response options not always accurately characterising their experiences, whilst other participants thought the survey was thoughtful, sensitive and useful in encouraging self-reflection. It is challenging to design a survey to suit every participant and strike an appropriate balance between convenience, brevity and level of detail needed for a meaningful analysis of the different outcomes. There was a sense that some participants wanted an opportunity to explain their numeric response in further detail, perhaps as they felt none of the available options captured their experiences. It is important to acknowledge that, in light of the sensitive and complex nature of the topic, it might have been difficult for some participants to rate their thought, feelings and experiences using Likert scales and they

may have felt more comfortable responding to questions in prose (Galasiński & Kozłowska, 2009). Then again, adding more open comment boxes or response options would have further complicated and lengthened the survey and for the purposes of the pilot RCT using quantitative rating scales was an important component. These factors impacted negatively upon the acceptability of the survey to some participants and might have contributed to participants withdrawing from the study prior to T1. For future research using similar measures, it would be helpful to examine which measures could be reworded to improve clarity and thereby increase the reliability of the results, or removed from the survey to shorten it.

Another limitation and future area for improvement involves the way change was measured in this study. As discussed in the empirical paper, there appeared to be a disparity between the change reported by participants in the satisfaction questionnaire and telephone interviews and changes captured by the outcome measures. For example, none of our outcome measures directly measured level of confidence and comfort in making disclosure-related decisions or feelings of isolation around one's experience of mental health problems. Additionally, whilst there was a quantitative measure of likelihood of disclosure, changes relating to disclosure seemed to occur in a more nuanced way for many people and, as one participant suggested, it may have been useful to "Differentiate thoughts, feelings and behaviours around disclosure so you can highlight which have changed (as I don't think all three have for me)." [P5] As mental health professionals in this study appeared to have quite low baseline scores on some of the outcome measures, it is possible that the measures used for this intervention in other samples are less applicable in this population. Therefore, one recommendation would be to collect more detailed qualitative data around the impact of the intervention and use the themes from this data to develop and validate suitable outcome measures for mental health professionals.

Data analysis. There were several limitations affecting the analysis and interpretation of the data. Firstly, if some of the measures were viewed as confusing or as ambiguously worded by participants, one cannot be certain that the responses

accurately reflect what the measure was intended to assess. This was particularly true for the Disclosure Distress measure and partially relevant to the Disclosure of Lived Experience (DOLE) measure which each comprised two separate scales. The Disclosure Distress scales each asked how distressed or worried participants felt in relation to 1. Keeping their mental health problem secret, and 2. Other people finding out about their mental health problem. When originally used in Rüsch et al.'s (2014) study, it was a single item ("In general, how distressed or worried are you with respect to secrecy or disclosure of your mental illness to others?"); we split this question into the two parts described above because we felt there was a difference in how one might feel in relation to actively trying to keep one's mental health problem secret versus how one might feel about others becoming aware of one's mental health problem. However, it would have been helpful to clearly explain our understanding of the differences between the two questions in the survey and explain what each is intended to capture, as some participants were unsure whether they answered them 'accurately'.

Similarly, it appeared that the survey was not clear on how some of the available response options were intended to be used. On the Disclosure Distress and DOLE measures, participants were able to respond with "I've already disclosed to them" or "Not applicable" if the other responses were not suitable to the type of person being rated (e.g. family member, supervisor, fellow trainee). However, when comparing the number of people selecting "I've already disclosed to them" at baseline compared to T1, it showed that the number had decreased overall even though it is generally not possible to retract a disclosure. It therefore appeared that participants interpreted the same questions at T1 as asking about new disclosures to that type of person since baseline, making the data invalid for the purposes of this study. Additionally, difficulties arose in relation to examining 'normality' on some of the measures included in our survey. For example, the outliers SPSS detected on the Disclosure of Lived Experience measure were simply those who were a little more or less open to disclosure than the majority of their peers which is to be expected on such a personal journey. Therefore, it felt

somewhat inappropriate to regard them as outliers; nonetheless, outliers had to be corrected in order to ensure assumptions for conducting ANOVAs were met.

In terms of the qualitative data, the analysis was mainly limited by the lower than hoped for number of participants who progressed to T1 and therefore completed the satisfaction survey, and having detailed qualitative data from only three telephone interviews. It might have been useful to download and analyse relevant content from the peer forum for additional data which is something follow-up studies in this area can consider.

Reflections on study findings and implications

Main learning points and recommendations for future research. After reflecting on the research process, the main learning points from this project which might be of use to fellow researchers would be to work in a suitably sized team and establish close working relationships with one's co-researchers and supervisors, to start the project as early as possible and allocate sufficient time to each stage whilst also anticipating the possibility of steps taking longer than planned, and to keep a record (e.g. meeting minutes, research log) of the research process which can be accessed later in the project when wanting to remind oneself why certain decisions were made. For follow-up studies specific to this project, it would be helpful to add to the knowledge gained from this study regarding the limitations of the outcome measures and factors reducing acceptability of the intervention in order to address these as best as possible. Once a fuller RCT has been completed, it would be beneficial to disseminate the findings and recommendations to participants and relevant organisations as indicated by research on participants' preferences for research dissemination (Long, Stewart, Cunningham, Warmack, & McElfish, 2016; Purvis et al., 2017).

Additionally, the sample in this study was homogeneous in terms of its demographic characteristics, with the majority of participants indicating they were white, female and heterosexual. Whilst clinical psychology is limited in diversity as a profession, future studies with larger samples could aim to examine differences in outcomes across demographic variables. People with multiple stigmatised identities face

additional barriers to disclosure and help-seeking (Arnold, Rebchook, & Kegeles, 2014), and it would be useful to examine whether this applies to mental health professionals with mental health problems and other marginalised characteristics or identities that are associated with health inequalities (Seng, Lopez, Sperlich, Hamama, & Reed Meldrum, 2012).

Implications for policy and practice. The generalisability of the findings is limited by the small sample size, although conducting an ITT analysis remedied this to some degree (Gupta, 2011). The baseline results from 51 participants who consisted predominantly of clinical psychologists (qualified and in training) suggested that participants in this study experienced a wide range of mental health problems (whether formally diagnosed or not), and that these have often been long-standing. This suggests that it might be helpful to think about mental health and well-being amongst mental health professionals both within and outside of the workplace. Nonetheless, the work environment is a context which can either be supportive or unhelpful depending on the workplace culture (Bronkhorst, Tummers, Steijn, & Vijverberg, 2015). Although in this study most participants indicated they had previously sought professional help, another recent study found that 16% of a sample of 425 clinical psychologists with mental health problems never sought professional help and this was significantly associated with impact on self-image and shame (Tay, 2016). Additionally, likelihood of disclosure in a professional context was low to moderate in this study, indicating that many participants choose not to seek support from their supervisor or colleagues.

A culture shift towards more supportive work environments which prioritise staff well-being and facilitate openness around experiences of distress and mental health problems to encourage help-seeking (including workplace adjustments) would be beneficial. This would not only help staff access timely support when needed but might also have a positive impact upon public stigma (Corrigan et al., 2012). Greater collaboration between different professional, regulatory and licensing bodies, researchers and employers could be one way of working towards a unified aim of a cultural change in the workplace.

Conclusion

This study has provided some insights into the value of interventions with a peer component that help mental health professionals reflect on their lived experience of mental health problems, carefully consider disclosure decisions, and discuss their experiences with their peers in a supportive setting. However, the process of developing an intervention, evaluation methods and trial procedures to suit the target population was challenging and there are several ways in which these could be revised and improved. The limitations and learning points described here may be of help for future follow-up studies and it is hoped that the ongoing research in this area will draw the support from organisations which can help create positive change to support mental health professionals to feel more confident about making disclosure-related decisions and seeking help if needed.

References

- Arnold, E. A., Rebchook, G. M., & Kegeles, S. M. (2014). 'Triply cursed': racism, homophobia and HIV-related stigma are barriers to regular HIV testing, treatment adherence and disclosure among young Black gay men. Culture, Health & Sexuality, 16, 710–722. https://doi.org/10.1080/13691058.2014.905706
- Brohan, E., Henderson, C., Wheat, K., Malcolm, E., Clement, S., Barley, E. A., ...

 Thornicroft, G. (2012). Systematic review of beliefs, behaviours and influencing factors associated with disclosure of a mental health problem in the workplace.

 BMC Psychiatry, 12. https://doi.org/10.1186/1471-244X-12-11
- Bronkhorst, B., Tummers, L., Steijn, B., & Vijverberg, D. (2015). Organizational climate and employee mental health outcomes: A systematic review of studies in health care organizations. *Health Care Management Review*, *40*, 254–271. https://doi.org/10.1097/HMR.0000000000000000
- Corrigan, P. W., Morris, S. B., Michaels, P. J., Rafacz, J. D., & Rüsch, N. (2012).
 Challenging the Public Stigma of Mental Illness: A Meta-Analysis of Outcome
 Studies. *Psychiatric Services*, 63, 963–973.
 https://doi.org/10.1176/appi.ps.201100529
- Galasiński, D., & Kozłowska, O. (2009). Questionnaires and Lived Experience:
 Strategies of Coping With the Quantitative Frame. Qualitative Enquiry, 16, 271-284. https://doi.org/10.1177/1077800409354068
- Gupta, S. K. (2011). Intention-to-treat concept: A review. *Perspectives in Clinical Research*, 2, 109–112. https://doi.org/10.4103/2229-3485.83221
- Joyce, T., Hazelton, M., & McMillan, M. (2007). Nurses with mental illness: Their workplace experiences: Feature Article. *International Journal of Mental Health Nursing*, 16, 373–380. https://doi.org/10.1111/j.1447-0349.2007.00492.x
- Joyce, T., McMillan, M., & Hazelton, M. (2009). The workplace and nurses with a mental illness. *International Journal of Mental Health Nursing*, *18*, 391–397. https://doi.org/10.1111/j.1447-0349.2009.00629.x

- Long, C. R., Stewart, M. K., Cunningham, T. V., Warmack, T. S., & McElfish, P. A. (2016). Health research participants' preferences for receiving research results. *Clinical trials*, 13, 582-591. https://doi.org/10.1177/1740774516665598
- Naslund, J. A, Grande, S. W., Aschbrenner, K. A., & Elwyn, G. (2014). Naturally

 Occurring Peer Support through Social Media: The Experiences of Individuals

 with Severe Mental Illness Using YouTube. *PLoS ONE*, *9*, e110171.

 https://doi.org/10.1371/journal.pone.0110171
- Norris, A. E., & DeMarco, R. (2005). The experience of African American women living with HIV: Creating a prevention film for teens. *Journal of the Association of Nurses in AIDS Care*, *16*, 32–39. https://doi.org/10.1016/j.jana.2005.01.002
- Pachankis, J. E. (2007). The psychological implications of concealing a stigma: A cognitive-affective-behavioral model. *Psychological Bulletin*, 133, 328–345. https://doi.org/10.1037/0033-2909.133.2.328
- Purvis, R. S., Abraham, T. H., Long, C. R., Stewart, M. K., Warmack, T. S., & McElfish, P. A. (2017). Qualitative study of participants' perceptions and preferences regarding research dissemination. *AJOB empirical bioethics*, 8, 69-74. https://doi.org/10.1080/23294515.2017.1310146
- Quinn, D. M., & Chaudoir, S. R. (2009). Living With a Concealable Stigmatized Identity: The Impact of Anticipated Stigma, Centrality, Salience, and Cultural Stigma on Psychological Distress and Health. *Journal of Personality and Social Psychology*, *97*, 634–651. https://doi.org/10.1037/a0015815
- Rao, A. S., Bhutani, G., Dosanjh, N., Clarke, J., Hughes, J. H., Easton, S., ... Cohen-Tovée, E. (2016). *Psychological Wellbeing and Resilience: Resetting the Balance*. Retrieved from https://www1.bps.org.uk/system/files/Public files/ar_v10_resetting_the_balance_160516.docx.pdf

- Rüsch, N., Abbruzzese, E., Hagedorn, E., Hartenhauer, D., Kaufmann, I., Curschellas, J., ... Corrigan, P. W. (2014). Efficacy of coming out proud to reduce stigma's impact among people with mental illness: Pilot randomised controlled trial.

 British Journal of Psychiatry, 204, 391–397.

 https://doi.org/10.1192/bjp.bp.113.135772
- Seng, J. S., Lopez, W. D., Sperlich, M., Hamama, L., & Reed Meldrum, C. D. (2012).
 Marginalized identities, discrimination burden, and mental health: Empirical exploration of an interpersonal-level approach to modeling intersectionality.
 Social Science & Medicine, 75, 2437–2445.
 https://doi.org/10.1016/J.SOCSCIMED.2012.09.023
- Severinsson, E. (2015). Rights and responsibilities in research supervision. *Nursing & Health Sciences*, *17*, 195–200. https://doi.org/10.1111/nhs.12160
- Tay, S. (2016). Lived Experience of Mental Health Problems among Clinical
 Psychologists, Stigma and its Impact on Disclosure and Help-seeking.

 (Unpublished doctoral dissertation). University College London, London, UK.

Appendices

Appendix A: Outline of each trainee's contribution to joint project

This was a joint project with another Trainee Clinical Psychologist at UCL. We worked together throughout the project but divided different tasks between us. For example, whilst working jointly on the adaptation and development of the HOP-MHP intervention, we were responsible for adapting and drafting different sessions of the HOP-MHP guide drawing on feedback from stakeholders and small pilot participants.

We worked jointly on recruitment but each focused on different recruitment strategies. Other tasks, including the drafting of the information sheet, consent form, study website content and email templates for participants, and the development of the web survey, were allocated to one of the two researchers to focus on initially. Once an initial draft had been developed, the other researcher would usually provide feedback and/or make revisions.

Both of us were allocated half of the participants in each study arm to whom we sent regular emails and whose progress we kept track of using a shared, anonymised progress tracker document. The data collected from participants was shared between our project but as we each focused on separate outcome measures and research questions there was only limited overlap (mainly in terms of the demographics and possibly some of the qualitative data).

We regularly attended joint research meeting with our supervisors, Dr Katrina Scior and Dr Henry Clements, in which we discussed research progress and challenges, allocated research tasks and, later on in the project, discussed plans for data analysis. My colleague and I also attended a meeting with a senior research associate to gain advice on some general questions relating to Intention to Treat analysis.

The data analysis and write-up of the empirical paper were completed independently.

Appendix B: Literature Review Quality Appraisal Scores

Quality appraisal scores of all studies included in this review

Study author(s) & date	Quality criteria (each scored from 1-4)									Overall Quality Appraisal scores (9-36)
	Abstract & title	Introduction & aims	Method & data	Sampling	Data analysis	Ethics & bias	Results	Transferability / generalisability	Implications & usefulness	
Buseh & Stevens (2007)	4	3	4	3	4	3	4	3	4	32
de Vries et al. (2016)	4	4	4	3	4	3	4	3	4	33
Donnelly et al. (2016)	3	4	4	3	4	3	4	3	4	32
Emlet (2006)	3	4	4	4	4	3	4	3	3	32
Frye et al. (2009)	4	4	3	3	4	2	4	3	4	31
Geary et al. (2014)	4	4	4	4	4	4	4	4	3	35
Heggeness et al. (2017)	4	4	4	3	4	3	4	3	4	33
Holt et al. (1998)	4	4	4	3	3	2	4	3	1	28
Li et al. (2016)	4	4	3	3	4	3	3	3	4	31
Lyimo et al. (2014)	4	3	4	2	4	2	3	2	3	27
Machtinger et al. (2015)	4	4	4	3	4	3	4	2	4	32
Norris & DeMarco (2005)	3	3	2	2	3	3	3	2	4	25
Parsons et al. (2004)	4	4	4	3	4	4	4	3	4	34
Paxton (2002)	4	3	3	3	1	2	4	2	3	25
Prati et al. (2016)	3	4	4	3	4	2	4	3	4	31
Swendeman et al. (2006)	3	4	4	4	4	3	4	4	4	34

Appendix C: UCL Ethical Approval Letter

UCL RESEARCH ETHICS COMMITTEE ACADEMIC SERVICES



27th September 2016

Dr Katrina Scior Research Department of Clinical, Educational & Health Psychology UCL

Dear Dr Scior

Notification of Ethical Approval

Re: Ethics Application 9297/002: Supporting disclosure related decisions among clinical psychologists experiencing mental health problems. A feasibility and pilot study

I am pleased to confirm in my capacity as Chair of the UCL Research Ethics Committee (REC) that your pilot and feasibility study has been ethically approved by the UCL REC until 1st January 2018.

Approval is subject to the following conditions:

- You must seek Chair's approval for proposed amendments (to include extensions to the duration of the
 project) to the research for which this approval has been given. Ethical approval is specific to this project
 and must not be treated as applicable to research of a similar nature. Each research project is reviewed
 separately and if there are significant changes to the research protocol you should seek confirmation of
 continued ethical approval by completing the 'Amendment Approval Request Form':
 http://ethics.grad.ucl.ac.uk/responsibilities.php
- 2. It is your responsibility to report to the Committee any unanticipated problems or adverse events involving risks to participants or others. The Ethics Committee should be notified of all serious adverse events via the Ethics Committee Administrator (ethics@ucl.ac.uk) immediately the incident occurs. Where the adverse incident is unexpected and serious, the Chair or Vice-Chair will decide whether the study should be terminated pending the opinion of an independent expert. The adverse event will be considered at the next Committee meeting and a decision will be made on the need to change the information leaflet and/or study protocol.
- 3. For non-serious adverse events the Chair or Vice-Chair of the Ethics Committee should again be notified via the Ethics Committee Administrator (ethics@ucl.ac.uk) within ten days of an adverse incident occurring and provide a full written report that should include any amendments to the participant information sheet and study protocol. The Chair or Vice-Chair will confirm that the incident is non-serious and report to the Committee at the next meeting. The final view of the Committee will be communicated to you.

On completion of the research you must submit a brief report of your findings/concluding comments to the Committee, which includes in particular issues relating to the ethical implications of the research.

Academic Services, 1-19 Torrington Place (9th Floor), University College London

Tel: +44 (0)20 3108 8216 Email: ethics/bucl.ac.uk http://ethics.grad.ucl.ac.uk/ **Appendix D: Information Sheet**

Information Sheet for the HOP-MHP Study

Supporting mental health professionals in considering disclosure of their own mental health problems through a self-help intervention

We are recruiting participants to take part in a pilot RCT of the new HOP-MHP self-help guide. We would like to invite you to consider participating in this research project, which is overseen by us and carried out by a research team at UCL

Dr Katrina Scior and Dr Henry Clements
Research Department of Clinical, Educational and Health Psychology
University College London
1-19 Torrington Place
London WC1E 7HB
United Kingdom
+44 (0)20 7679 1897
k.scior@ucl.ac.uk henry.clements@ucl.ac.uk

This study has been approved by the UCL Research Ethics Committee (Project ID No.: 9297/002).

Overview

This study will test the delivery and impact of a new self-help intervention (HOP-MHP, short for *Honest Open Proud for Mental Health Professionals*) designed to support mental health professionals (including those in training) in reaching decisions relating to the disclosure of mental health problems they may be experiencing or may have experienced in the past. If you personally have lived experience of mental health problems and you are not currently completely 'out' about this in both your social and work circles, you may find this intervention helpful.

Using the self-help guide will help you personally consider whether, where and how you may want to disclose your own lived experience. For the duration of the study, you will also have access to an anonymous peer forum where you can discuss your experiences and thoughts regarding disclosure with other mental health professionals with lived experience.

Aim of the HOP-MHP project

The aim of the HOP-MHP project is to test the feasibility, acceptability and effectiveness of a self-help intervention to support mental health professionals (qualified and still in training) in reaching decisions relating to the disclosure of mental health problems they may be experiencing or may have experienced in the past. The aims of the intervention are to reduce stigma stress, disclosure-related distress and empower participants in deciding for themselves if and how they want to talk about their lived experience. Through access to a peer forum we are also looking to provide opportunities for support from colleagues with lived experience. HOP-MHP is based on a manualised group intervention called Honest, Open, Proud (HOP), which was developed by Professor Patrick Corrigan and colleagues at the Illinois Institute of Technology, as part of the US National Consortium on Stigma and Empowerment.

The project follows on from research that shows that significant proportions of mental health professionals have lived experience but that many are reluctant to disclose their experience, particularly in a work and professional context, due to fears about negative consequences and a perceived lack of appropriate support.

Who can participate?

Anyone interested in participating in this project must meet all of the following criteria:

- (1) They are a qualified or trainee mental health professional and a UK national or resident;
- (2) They have current or past lived experience of mental health problems;
- (3) They would like an opportunity to consider whether or not they would like to be (more) open about their lived experience in social and/or work settings. The intervention is designed for anyone who up to this point has chosen either to keep their lived experience private in all or some settings and relationships and who would welcome an opportunity to consider in depth whether to disclose their lived experience more widely or in different contexts. As such it is not suitable for anyone who is already entirely open about their lived experience in their social and professional circles.

Participation is voluntary and choosing not to take part will not disadvantage you in any way. Before you decide whether you want to take part, it is important for you to read the following information carefully and discuss it with others if you wish. Please contact us if there is anything that is not clear or if you would like more information.

What does participation involve?

If you decide to take part in this pilot RCT, please return the completed consent form and screening questionnaire to the research team. If you meet the project's inclusion criteria you will then be asked to complete a number of outcome measures through a web survey – these relate to mental health stigma, disclosure, past and present mental health problems you may have experienced, and demographics. The survey will take approximately 15 to 20 minutes to complete. Once you have completed the survey and it has been confirmed that you meet the inclusion criteria, you will be informed whether you have been randomly allocated to the intervention or control arm. You will have a 50:50 chance of being allocated to either the intervention or the control/delayed intervention arm.

If you are assigned to the <u>intervention arm</u>, you will be sent the HOP-MHP self-help guide. This consists of three sessions and some follow-up activities. You will be asked to complete the three sessions and follow-up at a time and place of your convenience - each session is expected to take approximately 1 to 1.5 hours to complete. You will be asked to complete the initial three sessions within around 3 weeks, i.e. one session per week. We will send you reminders and will be available throughout to respond to any queries you may have. You will also have access to information relevant to mental health professionals with lived experience including resources providing support and advice.

After completing the three sessions you will be asked to complete the survey again. We will then send you the follow up session of the HOP-MHP guide one month later. After completing the follow-up session, you will be asked to complete the survey one final time and will also be invited to take part in a 30-minute telephone interview about your experience of the self-help guide and the survey. You can choose whether or not to participate in an interview after completing the intervention.

While you are using the HOP-MHP guide you will also have the opportunity to use an anonymous online peer forum for the duration of the study. Our choice of an anonymous web based peer support forum is based as much on our belief in the value of peer support as it is on evidence on the benefits of peer support.

If you are assigned to the <u>control arm</u>, you will have access to information that is relevant to mental health professionals with lived experience including information about resources providing support and advice. You will also be asked to complete the second survey three weeks after completing the baseline survey and the final survey one month later. Once you have completed all three surveys you will be sent the HOP-MHP self-help guide and will also be given access to the anonymised online peer forum at that point.

Anonymity and Confidentiality

The project is carried out by a team at UCL involving, in addition to the two project leads, research staff as well as trainee clinical psychologists. The project will be carried out in a way that strictly protects participant confidentiality by storing any personal identifiable data securely in the UCL Data Safe Haven. All project data will be stored according to the Data Protection Act 1998.

The outcome measures will be completed through a web survey using a programme called Qualtrics. You will <u>not</u> be asked to provide any of the completed worksheets that are part of the HOP-MHP self-help guide. Your contributions to the peer forum are anonymous (as long as you sign up using an alias e-mail address and user name) and may be used as data in future research - you can opt out of your data being used in this way by sending an e-mail to hopproject@ucl.ac.uk. This will not affect your access to or ability to engage with the peer forum in any way.

Benefits and risks

We anticipate that participating in the project will be helpful in supporting you to make decisions in relation to disclosure or non-disclosure of lived experience. We also anticipate publishing the outcome of the completed study, and we hope that it will have a positive impact on encouraging greater openness to lived experience and in tackling mental health stigma within the mental health professions and beyond.

It is possible that reflecting on your current or past difficulties and thinking about disclosure while you participate in the study may cause you distress. If that is the case and you would like to discuss this, please contact the project's Clinical Lead, Dr Henry Clements (henry.clements@ucl.ac.uk; tel. 0207 679 1897). Henry will be happy to speak with you on a confidential basis and to help signpost you to appropriate support. If he is unavailable then please contact the Project Lead, Dr Katrina Scior (k.scior@ucl.ac.uk; tel. 0207 679 1897). Please do also access one or more of the suggested sources of support listed on the following webpage, especially if you need urgent help: https://www.ucl.ac.uk/pals/research/cehp/stigma-

research/documents/hop_docs/hop_additional_resources

How do I participate?

The consent form and screening questionnaire are available from the HOP-MHP web page: (http://www.ucl.ac.uk/pals/research/cehp/stigma-research/research) Communications as part of this project will be conducted via email. As such a first step in taking part is to identify an email address you are comfortable to use for this purpose. We recommend participants set up an alias email address, such as a Gmail address. Setting up a new Gmail address for this purpose is fast and easy and will make you non-identifiable to the research team. However, the choice is entirely yours - throughout we are keen to respect participants' choices and to make sure that what we offer feels comfortable and safe.

Importantly, if you do set up a new email address for the purpose of participating in this study, it is vital that you make a record of the address and your password. We would also strongly advise you to set up message forwarding from any new email address you set up to the email address you use most frequently to ensure that all communications from the project team reach you. Instructions on how to do this are available at https://support.google.com/mail/answer/10957?hl=en

Your participation in this project is voluntary and you are free to withdraw from the project at any time and without giving any reason.

Thank you very much for considering taking part in this project.

Appendix E: Consent Form and Brief Screening

Informed Consent Form for Participants in the pilot RCT of the HOP-MHP Self-Help Guide

Supporting mental health professionals in considering disclosure of their own mental health problems through a self-help intervention

Please complete this consent form and the screening questions after you have read the Information Sheet (available to download at http://www.ucl.ac.uk/pals/research/cehp/stigma-research/research)

This study has been approved by the UCL Research Ethics Committee (Project ID No.: 9297/002).

Thank you for your interest in taking part in this research study. If you have any questions arising from the Information Sheet or explanation already given to you, please ask the researcher before you to decide whether to join in. Please retain a copy of this Consent Form to keep and refer to at any time.

Participant's Statement

- I have read the notes written above and the Information Sheet, and understand what the study involves.
- I understand that it is my choice whether to use a personal email address or to set up a new Gmail address for the purpose of the study to help protect my confidentiality.
- I understand that if I decide at any time that I no longer wish to take part in this project, I
 can notify the researchers involved and withdraw immediately, without having to give any
 reason.
- I consent to the processing of my personal information for the purposes of this research study.
- I understand that such information will be treated as strictly confidential and handled in accordance with the provisions of the Data Protection Act 1998.
- I agree that the research project named above has been explained to me to my satisfaction and I agree to take part in this study.

☐ I consent to take part in the research project as outlined in the Information Sheet
The email address I would like to be used for the purpose of this research is:
(please print very clearly)
Date:

Please ensure you also complete the screening questions on the next page

HOP-MHP Screening Questions

Please answer all four questions below to ensure that you meet the inclusion criteria for the HOP-MHP study. For each item please place a tick under yes or no.

1.	Are you a me	ental health profession	nal (whether qualified or in training)?
		□ Yes	□ No
2.	affected your		encing a mental health problem that has way either at present, or have you experienced
		□ Yes	□ No
3.			eriences of mental health problems, that is have It there is little place for thinking about future
		□ Yes	□ No
4.		•	have you been bothered by thoughts that you ting yourself in some way?
		Please select one of □ 0 – Not at all □ 1 – Several days □ 2 – More than ha □ 3 – Nearly every	alf the days

If you have selected 3 ('nearly every day') on item 4, we advise that you should seek urgent support, either through NHS services or through crisis services – you can find more information about accessing support on our web page:

http://www.ucl.ac.uk/pals/research/cehp/stigma-research/documents/hop_docs/hop-mhp At the present time, we think this needs to be a priority and that engaging with this study is not in your best interests.

If you have answered 'no' to items 1 and 2, or 'yes' to item 3, you do not meet the inclusion criteria for this study.

Thank you for your interest in our research study.

Appendix F: Participant Email Flowchart

Screening	Baseline	Allocation / Sent HOP- MHP	HOP-MHP Session 1	HOP-MHP Session 2	HOP-MHP Session 3	Time 1 (T1) [or dropout email if no response]		HOP-MHP Follow-up	Time 2 (T2)	T2 Qualitative Interview
Information sheet Consent Form Screening Form	Those eligible were sent personalised link to Baseline survey.	Participants were informed of allocation to intervention arm and sent HOP-MHP guide and info re: accessing peer forum.	encour per ses Weekly	"There are different ways to disclose" cants were aged to take sion but time y emails sented researched	e varied.	Once a participant indicated that HOP-MHP sessions 1-3 had been completed, the allocated researcher sent them a personalised link to T1 survey.	Approx. Four Weeks Later	Participants were thanked for completing the T1 survey and sent the HOP-MHP Follow-up Session. Researcher reminder e complete F sessions an if applicable	mails to ollow-Up d T2 survey	Telephone interviews to gain acceptability and feasibilit feedback were completed with those who consented.
						A reminder email to complete T1 survey was sent if needed.				
Preparation	Week 0	Week 1	Week 2	Week 3	Week 4	Week 5		Week 8	Week 9	Week 10

Screening	Baseline	Allocation	1	Time 1 (T1)	٠	Time 2 (T2)
Information sheet Consent Form Screening	Those eligible were sent a personalised link to the Baseline survey.	Participants were thanked for completing the baseline survey and informed of allocation to control arm.	Three to Four Weeks Later ping in touch'	Participants were sent a personalised link to T1 survey. A reminder email to complete the T1 survey was sent if needed. A dropout email was sent if no response following reminder email.	Approx. Four Weeks Later	Participants were sent a personalised link to the T2 survey. Once they completed this, they were sent the full HOP-MHP guide and information on how to access the peer forum.
Form		emails sent k	by the	'kee	icipants were sent ping in touch' emai	ls
	Week 0	Week 1		Week 5		Week 9

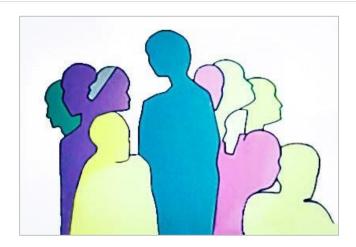
Appendix G: HOP-MHP guide cover and contents pages



HONEST, OPEN, PROUD

To Eliminate the Stigma of Mental Health Problems

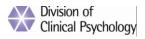
A Self-Help Guide for Mental Health Professionals



Katrina Scior, Henry Clements, Anna Hildebrand, Harriet Mills, and Patrick W. Corrigan







 $\label{eq:honest} \begin{aligned} & \text{HONEST, OPEN, PROUD} - \text{MENTAL HEALTH PROFESSIONALS} \\ & \text{SELF-HELP GUIDE} \end{aligned}$

© 2017 Scior, Clements and Corrigan

The authors have asserted their rights in accordance with the Copyright, Designs and Patents Act 1988, to be identified as the authors of this work. All rights reserved. With the exception of the permission given below, no part of this publication may be reproduced, stored in a retrieval system, or transmitted in any form or by any means, electronic, mechanical,

photocopying, recording or otherwise, without the prior permission in writing of the copyright

owner.

Photocopying/printing permission

Materials contained within this manual including worksheets may be printed or copied without fee or prior permission subject to the following condition: none of the materials are used for

commercial purposes.

This guide is to be used in conjunction with the HOP-MHP website:

https://www.ucl.ac.uk/pals/research/cehp/stigma-research/documents/hop-docs

For more information about the original Honest, Open, Proud programme visit:

www.hopprogram.org

All illustrations by Ashley Boscoe: ashley.boscoe.15@ucl.ac.uk

Acknowledgements

We are indebted to the original authors and other members of the HOP 'community' for their

support in developing this self-help guide. In particular, we thank Pat Corrigan for his

enthusiastic support in all aspects, and Nicolas Rüsch for his support with the evaluation. We

also thank the many mental health professionals who generously gave up their time to help us in developing this self-help guide. Last but not least, we thank Ashley Boscoe and Siir Saydam

for their assistance with this project.

152

CONTENTS

PREFACE	4
SESSION 1	10
Considering the Pros and Cons of Disclosing	10
SESSION 2	24
There are Different Ways to Disclose	24
SESSION 3	48
Sharing Your Experiences	48
APPENDIX	61

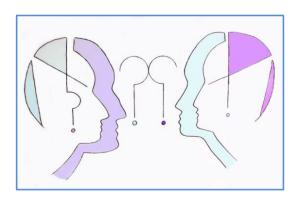


HONEST, OPEN, PROUD

To Eliminate the Stigma of Mental Health Problems

A Self-Help Guide for Mental Health Professionals

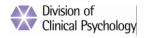
FOLLOW-UP



Katrina Scior, Henry Clements, Anna Hildebrand, Harriet Mills, and Patrick W. Corrigan







Appendix H:	Participants' d	lescriptions o	of their menta	I health problems

- "I think my difficulties were exacerbated by situational aspects, but had underlying origins in difficulties experienced at school. The pressures of training and events of perfectionism and desire to be a 'perfect' trainee was a catalyst." [P3]
- "I am largely recovered, but my prior mental health difficulties do cause difficulties every now and again. I continue to experience anxiety, and am prone to mood fluctuations. Stress exacerbates this and I try to take good care of myself so that I remain well. Historically, I had an eating disorder, significant and debilitating anxiety and depression. I self harmed regularly for many years." [P7]
- "I have (had?) a phobia that I've had for as long as I can remember. I had CBT which has helped me massively." [P8]
- "(...)I continue to hear voices daily (...), at times of stress experience delusional thoughts, paranoia and thought difficulties which make it hard to communicate with people. I don't really experience mood problems anymore but I do take a heavy dose of mood stabiliser (...)." [P10]
- "I would explain my difficulties is terms of learning not to express my emotions from a young age in order to avoid feeling rejected or criticised and the fact that this causes conflict with other goals such a being able to develop close personal and professional relationships." [P11]
- "Struggle with mania and depressive episodes and previously have had difficult visual and audio hallucinations which felt to link to trauma experiences at the time." [P12]
- "I didn't have secure attachment when I was small, I witnessed domestic violence and had emotionally distant parents, I grew up in an invalidating environment. I suffered trauma throughout my teenage years. Because of all that I developed complex PTSD and Dissociative problems." [P15]
- "Social anxiety. I understand it as stemming from early negative childhood Experiences. I feel I have managed well the last 4 years, however beginning training and the stress of this has made me feel vulnerable to another episode." [P16]
- "I can struggle with health anxiety, initially triggered by chronic back pain and stress. (...). I have used maladaptive coping strategies such as drinking more alcohol." [P18]
- "An OCD-type reaction to extreme stress and feeling uprooted/change." [P23]
- "Depression that becomes triggered with numerous stressors when my coping strategies have depleted." [P26]

- "I have a significant history of struggling to regulate mood and feel secure in attachment relationships. I understand this in terms of repeated difficult experiences in formative early relationships, which made it hard to develop a sense of internal safety and stability in relation to myself and others." [P33]
- "I think I have traits of personality disorder." [P34]
- "Stress gets to me; need to be constantly watchful; afraid of relapse experience what you might call depression, anxiety, and slightly altered states with mild paranoia." [P36]
- "I experience recurring bouts of severe anxiety and depressive type symptoms, related to previous traumas and possibly a genetic predisposition. I also suffered badly with perinatal anxiety and severe post natal depression with psychotic symptoms (...)" [P40]
- "I guess the easiest label to give is depression. however, it's not a term i particularly use. feeling lonely, low, tired, less motivated, less happy, difficulty in making decisions. being very self critical, low in confidence, feeling unattractive and unintelligent. feeling I can never do anything well enough." [P43]
- "'Struggle' is probably a strong word, I still think about my experience a lot and it causes me to feel defective and ashamed as a mental health professional at times. (...). My own difficulties have given me a huge deal of insight and definitely shaped my decision to train as a psychologist and enhanced my ability to empathise with clients I work with." [P48]
- "I conceptualise the mental health difficulties I have experienced in the past as being the by-product of a traumatic/neglectful childhood, which had left me more vulnerable to managing stressful situations in adulthood. I have previously engaged in therapy and have been able to make sense of the chaos that surrounded my formative years, but I know that I am still at a higher risk of struggling with my emotional response in particularly stressful situations." [P54]
- "As a result of difficult family dynamics while growing up, I struggle with feelings of guilt and over-responsibility and can find it difficult to regulate my emotions. I tend to lean towards 'unhealthy' coping strategies such as disordered eating and self-harm which started in my early teens when I had no other outlets or ways in which to manage my emotions. I no longer struggle as much but at times I can find things very difficult and become overwhelmed." [P57]
- "A pattern of behaviour in response to internal and external events. The result of chemical imbalance, genetics, social environment, individual thinking patterns etc." [P61]

Appendix I: Additional quotes regarding the acceptability of the intervention and measures

N.B. Only those acceptability categories with additional relevant data have been included here.

3. Effectiveness or helpfulness.

The intervention prompted some participants to reflect on new options or ways to disclose and consider potential positive aspects of their lived experience.

"I think I had a quite split view if that makes sense (...), whereas I think actually going through the pros and cons sheet sort of made me have a bit more of an integrated view, thinking like 'Okay, there are times when it might be helpful, times when not', and just yeah, a bit more realistic view. I think now I still have a positive view of it but also one that sort of takes into account that it's not one or the other, that actually it's a bit of both."

"I suppose I'm now more open to think about the potential benefits of my experiences, rather than how terrible they were." [P48].

It also helped some participants feel more prepared for disclosure and more aware of their disclosure goals.

"I think I probably feel a bit more comfortable about it and that I put more thought into it. I have previously before this study made a couple of disclosures at work about my own mental health history and they haven't been particularly well received, erm but I think partly that was because I hadn't really put that much thought into what I was saying or why I was saying it, erm, and I wasn't really entire sure what I was expecting, so I think it has been helpful for me to think that through." [P27]

For several participants the impact of the intervention was the start of a more nuanced, longer term process and rather than a direct behaviour change.

"It's facilitated the thinking about it and it's given me permission to... take my time to make that decision. Because once disclosed I can't take it back and that was helpful, and I got that from the guide. It's obvious too but it was helpful to just see it; yes, so, you

can't ask people to unknow things about you. And while we know that, it's good to also make it clear to ourselves." [HOP 2]

"I felt more like I would disclose and planned to, to a friend, but then actually didn't do it when the time came. So it impacted on my decision, but not my behaviour." [P5]

"I haven't disclosed to anyone new but I think I have, what I have done is I think I've just been a bit more open generally (...) I think I have just been able to have more conversations around that and a kind of group meeting about sort of well-being, and I sort of said "Oh you know I think that there isn't really a space for people sometimes to talk about when things aren't going great", and just sort of said "I know I've had that kind of stuff going on", so it's not necessarily just about disclosing the sort of like "Oh, I'm incredibly messed up" or something like that but just saying like, you know, like a sort of micro-disclosure almost in a way." [HOP6]

Some parts of the intervention felt more or less helpful than others.

"I didn't particularly need the bits where it was suggested 'think about sounding out a colleague and how you would go about sounding out a colleague and maybe think about a situation and a movie that you discuss'." [HOP 2]

"I couldn't really sort of identify with most of those pros, there was quite a lot about sort of mutual support and stuff, and I guess that's something that can be helpful for many people but that's not really what I was thinking of. So, the one that I think was relevant was sort of the idea of, I guess – I don't know if I'm making this up but I think there was something about 'fighting stigma' or something like that and I think that is important."

[HOP 6]

The outcome measures also appeared to have an effect on participants in terms of becoming more aware of their attitudes towards disclosure and accessing professional support or simply allowing them to reflect on the topic.

"[The measures] helped me to think and reflect." [P36],

"It made me aware of how important it is to me to not use services, to deal with my problems myself. I am really horrified when I think what my life would be if I still used services. as other friends and relatives do." [P34]

4. Adverse effects or risks:

Some of the worksheet may have felt more challenging to complete than others which one participant described as frustrating.

"(...) The worksheets I remember finding quite difficult was, erm... 'developing a narrative'... it's not 'not helpful', it's just very difficult I think. So, I think that's another one I will probably revisit. It's not that it's wasn't helpful, it's just that I found it tricky... to really come up with anything. And that kind of frustrates a little bit. It's just sort of... it's helpful, it's important to think about but I think it's one that you need to invest some time in and I don't know whether I wasn't quite doing that." [P6]

6. Additional comments on the forum

Those use used the forum described how the conversations that took place and the responses they got felt validating, supportive and normalising and helped reduce isolation:

"(...) It was surprising how many people had similar experiences. Because you know, I thought that people would be quite vague about things and be like "Oh, you know, I had a period of, I don't know, sadness or something like that" where you think like "Well, okay, that is something but it's not very specific" but people were actually quite specific in saying you know, "I had this and that" and I didn't think that, I didn't expect that, so that was helpful." [HOP6]

"I'd sort of write something and then feel really anxious about what other people would say. But then found it really validating and really supportive and really interesting, actually. And I sort of still... I haven't written anything for a while but I sort of dip in and out of reading it... because I do feel that people have sort of really said things that really resonate. (...) I think it was really, erm... So, I'm going to use the word enlightening but

it feels like a bit of an extreme word, but to think... so I have come into this profession partly because of my own experiences and then have often felt really ashamed about that. But to hear other people commenting on that in a very similar way, and how they kind of negotiate those bits of themselves felt really validating just to read and hear and think: "Well, of course, like of course we have all experiences like this". And that's, I think, been really helpful for me." [HOP 23]

"It was easy to access and felt like a safe environment." [P8]

"I loved reading other people's reflections and their experience of either disclosing or not disclosing and what had happened as a result. What particularly stuck with me was the account of someone who [confidential] had an awful time in terms of disclosing, and some other people who had a good time, and how we all – the kind of experiences of mental health that carry into our profession that might be key to us choosing our profession and some people have been quite generous with their trust, and that was good to see. So that in itself was helpful in terms of [inaudible] the group reducing isolation and helping each other. Even though doing it via a virtual forum is very light touch, it's still much better than not doing it at all." [HOP 2]

Anonymity was described as a helpful aspect of the forum.

"It helps because it's anonymous, I can just say all sorts of things and... you know, like there were things that I know at this stage I wouldn't really tell anyone without sort of maybe working up to or thinking about." [HOP6]

However, concerns about anonymity and limited clarity around how to register anonymously appeared to be potential barriers to using the peer forum.

"When you follow the emailed link to Slack, the forum immediately registers your full name, which means you have to be conscious about taking the time to go into your profile and conceal your identity if this is what you choose to do. It doesn't prompt you to do this - I only realised by looking on my profile. I'm not sure if everyone is aware of this, even now." [P10]

"Maybe make it clearer that the name you enter will appear on screen. I inadvertently saw and recognised the (unusual) real name of a former colleague before she changed it, and I am guessing she was caught out by this." [P31]

Whilst the registration procedure was outlined in the forum joining instructions sent to participants, stating again in the body of the email that the name they choose to sign up with will initially appear as the profile name (but can be changed later) may have been helpful.

Another potential barrier included initial anxiety about making a first post or finding a way to join the existing conversation:

"I still took some time before I actually posted because I needed to sort of find something where, like a way in I guess, I didn't really have anything to say particularly, I thought, but then when someone said something I was like 'Ah wait' and then I just jumped straight in." [P6]

Several participants provided feedback on how to improve the design or layout of the forum, suggesting that it would be helpful to have different threads or topics rather than one main 'channel' as this made it more difficult to keep track of conversations or interrupt a conversation with a new topic:

"Have different sections to talk about the different aspects of the workbook. It was difficult to follow all the different conversations going on." [P18]

"[Add] sub-forums and threads so people can talk about specific things. E.g.

Introductions sub-forum, Questions about the guides, Questions about the worksheets & thread for each of the worksheets (for example)." [HOP 6]

"Maybe to post questions/ topics for people to think about? Really liked the conversation and to hear the perspectives of others." [P27]

Means* (SDs) and statistics from ANOVAs on original data (non-ITT)

Outcome measures	Mean (<i>SD</i>) at T0	Mean (<i>SD</i>) at T1	F-statistic (interaction)	<i>p</i> -value	Cohen's d
Stigma Stress Intervention (n = 13) Control (n = 18)	-1.17 (1.63) -0.50 (1.92)	-1.22 (1.50) -0.81 (1.54)	0.24	.625	0.186
Secrecy Scale Intervention (n = 13) Control (n = 18)	2.23 (0.52) 2.26 (0.48)	2.04 (0.53) 2.30 (0.52)	3.76	.062	0.730
Disclosure Distress – Being Found Out: Social Network Intervention (n = 11) Control (n = 17)	3.21 (1.80) 3.63 (1.31)	3.00 (2.08) 3.20 (1.34)	0.17	.688	0.163
Professional Network Intervention (n = 11) Control (n = 18)	4.64 (1.97) 3.98 (1.58)	3.44 (1.99) 4.16 (1.64)	7.99	.009	1.121
Healthcare Prof. Intervention (n = 7) Control (n = 10)	2.00 (1.53) 2.80 (1.75)	1.29 (0.49) 2.20 (1.32)	0.02	.879	0.081
Clients** Intervention $(n = 12)$ Control $(n = 18)$	3.26 (1.58) 3.91 (1.18)	3.67 (2.45) 4.72 (1.66)	0.347	.560	0.227
Disclosure Distress – Keeping it secret: Social Network Intervention (n = 13) Control (n = 18)	4.11 (2.00) 3.91 (1.65)	2.67 (1.15) 2.61 (0.94)	0.06	.812	0.09
Professional Network Intervention $(n = 12)$ Control $(n = 18)$	3.18 (1.77) 4.16 (1.28)	3.42 (1.57) 3.64 (0.93)	1.98	.170	0.543
Healthcare Prof. Intervention $(n = 10)$ Control $(n = 8)$	1.90 (0.74) 3.25 (1.39)	2.10 (1.29) 2.63 (1.41)	0.94	.347	0.488
Clients Intervention $(n = 12)$ Control $(n = 18)$	4.50 (1.92) 3.61 (1.47)	3.25 (2.16) 3.42 (2.13)	1.11	.300	0.407

Outcome measures	Mean (SD) at T0	Mean (SD) at T1	F-statistic (interaction)	<i>p</i> -value	Cohen's d
DOLE – past					
Social Network					
Intervention $(n = 12)$	3.83 (1.69)	3.83 (1.34)	0.51	.483	0.274
Control $(n = 18)$	4.01 (1.38)	3.63 (1.47)			
Professional Network					
Intervention $(n = 12)$	3.37 (1.61)	3.36 (1.28)	0.73	.402	0.328
Control $(n = 18)$	4.33 (1.18)	3.93 (1.41)			
Healthcare Prof.					
Intervention $(n = 3)$	4.67 (2.52)	4.67 (1.53)	2.93	.125	1.320
Control $(n = 7)$	5.57 (0.98)	4.14 (1.86)			
Olianda					
Clients	0 E0 (4 00)	2.02.(4.42)	4.04	075	0.400
Intervention $(n = 12)$	2.58 (1.26)	2.92 (1.40)	1.24	.275	0.429
Control $(n = 18)$	3.06 (1.49)	3.00 (1.47)			
DOLE procent					
DOLE – present					
Social Network	4.26 (1.15)	4.08 (1.48)	0.00	.964	0.018
Intervention $(n = 11)$	4.19 (1.77)	3.98 (1.40)	0.00	.304	0.010
Control $(n = 17)$	4.13 (1.77)	3.30 (1.07)			
Professional Network					
Intervention $(n = 11)$	3.29 (1.64)	3.75 (1.71)	1.75	.197	0.532
Control $(n = 17)$	4.27 (1.16)	4.11 (1.27)	1.75	.107	0.002
Ochiror (11 = 117)	4.27 (1.10)	4.11 (1.27)			
Healthcare Prof.					
Intervention $(n = 7)$	5.57 (2.23)	4.00 (2.16)	1.11	.305	0.513
Control $(n = 14)$	5.57 (1.02)	4.86 (1.70)			
,	` ,	,			
Clients					
Intervention $(n = 10)$	1.85 (0.91)	1.55 (0.72)	0.30	.589	0.227
Control $(n = 17)$	2.53 (1.37)	2.47 (1.23)			
COMIS					
Benefits of Being Out					
Intervention $(n = 13)$	3.99 (0.92)	4.20 (0.82)	1.01	.324	0.383
Control $(n = 17)$	4.53 (0.78)	4.51 (0.47)			
Reasons for Staying					
In	5.40 (0.90)	5.18 (0.63)	0.05	.821	0.087
Intervention $(n = 13)$	5.52 (0.75)	5.24 (0.85)			
Control $(n = 17)$					
E to the CB' of					
Extent of Disclosure	4.00 (0.54)	4.00 (0.54)	0.40	754	0.400
Intervention $(n = 21)$	1.62 (0.51)	1.62 (0.51)	0.10	.751	0.122
*Moone and SDs are based	1.59 (0.51)	1.65 (0.49)			

^{*}Means and SDs are based on ANOVA results. ANOVAs automatically exclude all cases which do not have data at all time-points. Therefore, the number of respondents for the different measures differs. **Levene's test was significant for T1 on this subscale making the result less valid.