Supporting mental health disclosure decisions:

The Honest, Open, Proud programme

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Summary

The stigma associated with mental health problems leaves many of those affected feeling they have to “hide” their difficulties. Supporting them in making disclosure decisions can potentially improve well-being, reduce self-stigma and support recovery processes. In this editorial we discuss the case for interventions designed for this purpose and present one prominent programme - Honest, Open, Proud.

Why focus on disclosure

Individuals experiencing mental health problems (and their families) face two primary challenges due to their mental health problems: first, the symptoms themselves, and second, stigma associated with these symptoms and diagnostic labels. While treatment innovations and services mainly address the former, stigma and its consequences often remain unaddressed, despite abundant evidence that stigma creates immense distress and inhibits recovery. Due to common negative stereotypes, many experiencing mental health difficulties not only experience discrimination but experience shame, think less of themselves, and feel they are somehow to blame for their difficulties. Stigma also leads many of those affected to feel that they have to “hide” their difficulties or diagnosis from others in order to avoid being viewed in a negative light and becoming the target of discrimination. While concealment may have real or perceived benefits for the person, a fear of “being found out” often creates additional stress and distress for the person. Secrecy can also act as a barrier to accessing informal and formal support, both central to recovery from mental health problems. Accordingly, supporting individuals to reach decisions around disclosure and act on these in ways that are personally meaningful and safe has multiple potential benefits and ultimately supports recovery processes through generating hope, reducing shame and enhancing self-esteem.

Supporting disclosure decisions

The most prominent approaches to supporting individuals in reaching careful disclosure decisions are Honest, Open, Proud (HOP) [1] and Conceal or Reveal (CORAL) [2]. They have some key differences. HOP (originally called ‘Coming Out Proud’) is a group programme, usually delivered over three sessions and considers disclosure across settings. A community based participatory model and empowerment are central to the ethos of HOP, and as such it is delivered as a peer-facilitated (or co-facilitated) group programme. In contrast, CORAL is a decision aid focused specifically on disclosure within an employment context and is usually delivered in one session by an employment adviser with a primary aim of reducing decisional conflict [2].

The HOP programme in particular has proven very popular with user groups and its dissemination and adaptation have developed rapidly. HOP in its original form or an adapted version is now being delivered in the USA, as well as Australia, Belgium, Canada, Chile, China, Germany, Israel, Italy, Switzerland, and the UK. Hence in this editorial we review some of the central premises of HOP, initial evidence on its impact, and consider the way forward for HOP and other approaches designed to support decisions regarding disclosure of mental health problems and other stigmatised conditions.

The Honest, Open, Proud Programme

Key premises of HOP are that disclosure of mental health problems is an individual and personal decision, that disclosure decision making is mostly an ongoing process (unless someone has very publicly 'come out'), and that the potential benefits and costs of disclosure vary depending on the context and need to be carefully balanced. Accordingly, HOP supports individuals in reaching careful decisions relating to disclosure of current or past mental health problems and planning actions informed by such decisions within a peer support setting. HOP does not shy away from fully recognising that disclosure can bring benefits but also poses risks. Hence it helps participants to weigh the pros and cons of disclosure and does not have the goal of persuading them to disclose but rather supports them in reaching a decision that feels right for them at a given moment in time. In the process, participants have the opportunity to construct a coherent narrative of their mental health problems, before deciding what, if anything, of this they want to share with others.

The programme is delivered using a manual and accompanying workbook, available on the programme website (http://www.honestopenproud.org). It is organised into three lessons plus a booster lesson, with a clear suggestion that participants draw on the materials and lessons learnt in revisiting disclosure decisions over time. In lesson 1, participants are encouraged to reflect on beliefs they hold about themselves and their mental health problems and to challenge hurtful, self-stigmatising beliefs. They are guided in carefully considering the potential benefits *and* costs of disclosing their mental health problems in different contexts, and weighing these up in reaching a decision about disclosure. In lesson 2, participants are introduced to different ways of managing disclosure decisions, such as social withdrawal to avoid 'being found out' at one end of the decision continuum, disclosure to selected individuals, and actively sharing one's experiences with mental health problems with others. Programme participants are guided in anticipating how others might respond. Lesson 3 supports participants in telling their personal story in a safe space by inviting them to write an account of their history of mental health problems, and in deciding what, if anything, they want to share, with whom, how and when. Those who decide to disclose are supported in considering carefully how to share their experiences. Finally, a booster session, in which

participants reflect on disclosure experiences and review their decision, takes place around a month after lesson 3. Those who decided against disclosure at the present time are encouraged to reflect on the benefits and costs of non-disclosure and to revisit their decision at intervals.

In addition to the original peer group version of HOP, various adaptations have been developed to tailor HOP to specific groups and cultural contexts, including versions for adolescents and college students, survivors of attempted suicide, parents of children with mental health problems, active soldiers and military veterans, individuals with Tourette Syndrome, those with a diagnosis of dementia, and mental health professionals.

HOP's Theory of Change

The central premise of HOP is that supporting disclosure decisions can reduce stress associated with stigma and a fear of 'being found out', self-stigma, empower individuals by increasing their self-efficacy in coping with stigma, and thus ultimately support the journey towards increased well-being and recovery.[1] This theory of change is partly supported by randomised controlled trials (RCTs) of HOP published to date, conducted with adolescents in Switzerland (N = 100) [3], and with adults in the USA (N = 126) [4] and Germany (N = 98). [5] Large reductions in stigma stress were observed in two of these trials ($\eta^2p = 0.15$ [3] and $d = 0.92$ [5]) and mixed effects on the two dimensions of stigma stress (perception of stigma as harmful to oneself and perceived resources to cope with such harm) in the third [4]. Self-stigma, a key target of the HOP programme, was reduced in two of the three studies. [4 5] In one of these [5], initial small effects on self-stigma (d = 0.36) increased to medium size effects at follow-up (d = 0.63). HOP's beneficial effects on the personally detrimental aspects of self-stigma (applying negative stereotypes to oneself and experiencing harm as a result of self-stigma) were maintained at 1-month follow-up ($p < .05$) in the other study.[4] The effect of HOP on self-stigma was negligible in the third study ($\eta^2p = 0.002$). [3] HOP showed large positive effects on disclosure-related distress and perceived need for secrecy at follow-up in the two studies that assessed these outcomes (both around $\eta^2p = 0.06$ in the Swiss study [3] and $d = 0.7$ in the German study [5]). Finally, help-seeking intentions increased at follow-up in the one study that examined them (d = 0.34 for family/friends, and d = 0.64 for professionals). [5] Thus evidence collected to date suggests that completing the HOP programme appears to leave individuals less concerned about having to conceal their experiences, less likely to apply negative stereotypes to themselves, and more likely to perceive themselves as able to deal with stigma. Of note, the outcomes of HOP vary somewhat across the studies conducted to date and should be viewed as tentative due to the small samples involved. The impact of HOP on access to both informal and formal support requires further evaluation as does the suggestion in one study [5] that HOP improves quality of life.

Future Directions

The HOP programme has proven popular with people with mental health problems and its dissemination and adaptation have developed rapidly. There are now HOP adaptations for different target groups. So far, RCTs have been published only about two of them, adults with mental health problems in community settings, and adolescents with mental health problems, most of them in inpatient settings. Several other trials are underway. None of the studies published to date are representative of all people with mental health problems struggling with public and self-stigma. For example, it is unknown how HOP affects individuals with mental health problems from diverse ethnic backgrounds.

Another consideration is that the assessed outcomes and associated measures in trials of HOP have varied, making comparisons across studies and samples more difficult. Hence a priority for the future implementation of HOP should be careful evaluation of outcomes and change processes. Attention will also need to be paid to ensuring that any new HOP sites and adaptations use a community based participatory approach which has been central to HOP's philosophy and practice from the outset.

In addition to a general need for larger, well designed outcome and process evaluations of HOP, ideally with representative samples, a number of questions should be the focus of further research. To date we do not know to what extent decisions in favour of disclosure or conversely non-disclosure mediate HOP outcomes. Feedback from HOP participants suggests that being given the opportunity to carefully consider whether, when, how and what one might want to disclose can lead to positive effects, regardless of whether the person ultimately decides to disclose. So those who decide to disclose while completing the HOP programme may experience reduced stigma stress and self-stigma, due to a reduced need for continued secrecy and concealment, while for those who decide not to disclose HOP may still bring benefits through empowered non-disclosure. Future research should test these hypotheses.

In view of evidence that direct contact with persons with mental health problems is the most effective strategy to reduce stigma, one would predict that increased disclosure as a result of engaging with programmes such as HOP would ultimately contribute to a reduction in public stigma. Assessing the impact of disclosure at an interpersonal and community level may render useful evidence to support efforts to reduce stigma. Therefore, future research should ask what effect witnessing a disclosure had on people's attitudes to those experiencing mental ill-health.

An important question is whether support for disclosure decision making should be available to anyone in a stigmatised group, for example as standard post-diagnosis, or

whether they should be targeted. In this context, a stepped care model may be worth considering, whereby anyone given a stigmatising diagnosis is offered some support to help them consider whether, how and with whom to share this, while those who are particularly concerned with secrecy and the risks of being found out have access to programmes such as HOP.

In the HOP programme family and friends are primarily characterised as people one needs to decide whether or not to disclose to. Going forward it may be helpful to make their potential role as allies to whom one may look for support in making and implementing disclosure decisions more explicit. However, what role they play will vary from person to person and a key aim of HOP is to promote self-determination in deciding who is safe and helpful to disclose to. In this and other aspects HOP's ethos of supported decision making is very different from interventions such as CORAL, which are about shared decision making between a professional and a stigmatised individual.

Conclusions

Programmes such as HOP address concerns about stigma and empower participants in taking control over disclosing their difficulties. By providing a non-judgmental forum for making disclosure decisions, programmes such as HOP help affected individuals problem-solve difficult decisions and act upon these in ways that are personally meaningful.

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