

Damned if you do. Damned if you don't.
Students' experiences of disclosing a mental health disorder

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Many people would have heard the "one in five" statistic often quoted when speaking of the prevalence of mental illness¹ in the broader Australian community. Many will also have heard that depression is expected to reach epidemic proportions in western society early in the new millennium.

Where are they all? Take a look around you, at your family and friends, your colleagues and acquaintances. Can you detect the "one in five"? Why can't we see them? There are two possible answers to this last question: because it is *you* or because one of the other four people is keeping it hidden from you. Mental illness, because of its 'invisibility' in many cases, needs to be disclosed to become evident. Most often, it requires self-disclosure. We shall discover in this paper that the disclosure of a mental health disorder is problematic for a number of reasons.

It is necessary for students of New South Wales Universities and Colleges of Technical and Further Education (TAFE) to disclose their mental health status in order to access the academic support services that are available to people with disabilities (McLean, Bardwell, Ryan & Andrews, 1998).

Reports from Disability Liaison Officers from a number of tertiary institutions suggest that there are relatively few people with a mental illness registered with student support services; certainly less than one in five.

According to the ABS National 'Survey of Mental Health and Wellbeing of Adults, Australia 1997' (Australian Bureau of Statistics, 1998b), 1508 (11.2%) of the 13,465 adults surveyed are post-secondary students. Of the 1508 students, 310 (20.6%) identify as having a mental health disorder. If we look at a Campus that services 3000 students, we can estimate that 20.6% or 618 students will have a mental health disorder.

¹ The terms 'mental illness' and 'mental health disorder' are used interchangeably in this paper. The latter is used by ABS in the 1997 National Survey on Mental Health and Wellbeing. The ABS survey included anxiety and affective disorders, substance use, and combinations of these with and without an accompanying physical condition. Schizophrenia was not included as a category for the ABS survey.

We cannot assume however, that all students with a mental health disorder will require academic support. A much more conservative estimate can be determined by excluding from the calculation, those students who indicated in the survey, that they had not used any health care or support service in the 12 months prior to their interview (Bathurst, 2000; Australian Bureau of Statistics, 1998a). This is a large proportion (62%) of the sample.

Thus, on a campus of 3000 students, the most conservative estimate of the number of students with a mental health disorder who are likely to require support is 234 or 7.8% of the campus population.

Reports from Disability Liaison Officers on campuses with 3000 students, indicate that the number of students with a mental health disorder accessing student academic support services in the year 2000, ranges from 5 to 11. A far cry from the estimated 234 students who potentially, will experience some degree of disability during any one year.

This is obviously a huge discrepancy for which there could be a number of explanations. The most likely explanations are: that the students are not aware that the support service is able to meet their needs; that they do not believe that they need support; or that they are not willing to disclose their mental health status (Bathurst & Grove, 2000).

We set out to examine disclosure more thoroughly. In response to a request for participation in our research project, seventeen students submitted narratives of their personal experiences of disclosing their mental health status at a tertiary institution.

This paper and presentation examines student's experiences of their disclosure of mental illness at University or TAFE, not only in regard to accessing support services and subsequent accommodations, but also in their day to day interactions in the higher education environment (Bathurst & Grove, 2000).

"Early days in the course -I was asked by the lecturer [who I had told], to share my experience of the luny bin with the class for their learning. I wouldn't do it again. It made for a very lonely way through" Karen.

We suspected that once we started to investigate incidences of students' disclosure a range of issues would emerge. Students may not consider their difficulties with depression or anxiety to be a mental health disorder. Students may not see support services as relevant: "access to a photocopier? Why would I need that?" Students may need to avail themselves of the special considerations that student support services provide but are loath to be known as 'sick' (Miles 1987 p73; Fitzgerald & Patterson 1995). Indeed, one of the most difficult tasks of our research was engaging students who had not disclosed to anyone at University at all. In order to attract students, posters were placed at various

campuses of Universities and colleges of TAFE around metropolitan and regional NSW, and strict confidentiality was assured at all times.

What we discovered were a number of issues that could be broadly broken down into the following themes:

- ◆ Some illnesses are better than others
- ◆ Stigma, stereotypes, ignorance and discrimination
- ◆ Reactions by staff
- ◆ Disclosing on a need to know basis
- ◆ Super-student and the importance of competence

Some illnesses are better than others

"... I also suffer from rheumatoid arthritis. Because my arthritis is visible and I have disclosed this, often this is taken as being the problem, which it is many times, but not always." Jane.

Many of the students reported issues directly related to the non-visibility or hidden nature of their disability and how those issues affected disclosure. Some students experience and exhibit behaviours which might, after a while, make it obvious that they have a mental health disorder but most state that they have no visible or obvious characteristics that would classify them as being ill or having a disability. Some students have reported that they do have symptomatic characteristics but they work hard to disguise them (Miles 1987 p104).

Students are aware that if 'special consideration' or accommodations are being utilised and they do not have an obvious physical disability, then other students and staff will deduce that the disability is a mental illness. One student, Karen, told a course colleague that she needed a separate exam room due to claustrophobia, "because schizophrenia sounded too scary".

The respondents seem to be aware of the hierarchy of stigma and that some conditions are more acceptable than others (Condeluci 1996). In fact some students specifically used a physical illness or disability (or even fabricated one) to explain away behaviours or special needs, rather than disclose their mental illness.

Stigma, stereotypes, ignorance and discrimination

"I have decided not to disclose next year. The attitudes towards disabilities of any kind are still Stone Age and mental illness is very misunderstood. People with mental illness are seen as crazy, dangerous, nuts, stupid and the list goes on. I know that by not disclosing, a drop in the standard of my work or the need for extensions may be mistaken as laziness. If the fact that I am not going to

disclose means that I will lose the support from the disabilities unit and the special exam conditions then I am just going to have to accept that." Sylvie.

Sylvie is correct in her assumption that people hold these views. People propagate many misconceptions about mental illness based on negative stereotypes that have been learned throughout one's lifetime (Miles 1987 p 63). Miles (1987) asserts that misconception is not the only factor contributing to negative stereotypes. "Lack of familiarity and general ignorance on the part of the public can be cited" (p64).

Stigma management can be achieved by concealing the stigmatised attribute. This concealment or hiding of the characteristics of the mental illness is known as 'passing' (Goffman, 1963; Miles 1987 p 104), and purposeful non-disclosure could be seen as an example. One student, Lisa, told us that even though she was good at pretending she was fine, the fact that she was in a very small course made her even more fearful of "people finding out" and making incorrect assumptions about her. This fear was stronger at her place of employment. She said, "she would rather die than disclose" to her employer or clients and saw that her "credibility would go out the window".

Similarly, we recall the comment of a student in a forum outside of this project. She stated that whilst the specially designated photocopier in the library (for people registered with Student Services) is really helpful, the fact that it is in full view of the long queue of people waiting for the regular photocopier makes it embarrassing to use.

Keiley would like to be more open but she fears being judged. "It has always been a sensitive issue". She wishes that a couple of trusted friends knew more so that she would have people to talk to. Her schizo-affective disorder presents as anger, which has caused her friends to distance themselves from her. Keiley is generally shy and silent particularly she says, "when I hear people speaking derisively or joking about mental illness". Like many of the other respondents, Keiley wants people to know her before disclosing because she doesn't want to be treated differently. She just wants to live normally and not have to worry about being embarrassed when "enrolling on the short queue".

Reactions by staff

"During his lecture later that day, he stopped and asked me if I understood what he had just said. He asked in front of a theatre of around 120 students if I understood. Why didn't he ask the group of students up the back having a conversation or the students down the front who were repeat students..." Sylvie.

Students reported a range of experiences upon disclosure, ranging from support and assistance to dismissal and discrimination. All respondents had at some

stage during their study, disclosed to either the counsellor or the student disability support services. Almost all of the respondents reported this disclosure and the resultant academic and personal support as being very helpful in getting through their course.

The reactions of academic staff generally however, are rather concerning. Open hostility, disbelief, insensitivity, minimisation of the illness and breaches of confidentiality were not uncommon experiences. In cases where academic staff reactions were positive and supportive, their actual responses were often inappropriate.

The lecturer to whom Sylvie disclosed and refers to in the quote above was very understanding and sympathetic. He just didn't know how to respond to her needs. Another student felt she was given advice that was meant to be sympathetic, but which came out as punitive and discriminatory. Both Elizabeth and Keiley disclosed their mental health status during class discussions about mental illness. In both cases, the reaction was silence, followed by the introduction of another topic. Both women were left hanging, without being able to process any potentially ensuing reactions. In Elizabeth's case, she became embarrassed, bewildered and upset. When confronted later, the lecturer admitted to not having known how to react. Whilst apologetic, he also wanted assurance that Elizabeth was not going to go crazy in front of him.

Paul stated that the majority of his teachers misjudged his actions in applying for extensions on his assignments and accused him of manipulation and abuse of the system. Paul is not the only respondent who had experienced hostility and the trivialisation of his illness. Other students have reported academics' refusal of requests for special conditions despite presenting official documentation that supported their claim.

The relationship between the reactions and responses of the academic staff to the student who discloses and the student's subsequent success or failure is a relationship that needs much more exploration. We see this relationship as pivotal to a student's overall experience of higher education.

Disclosing on a 'need to know' basis

"Generally speaking I have only disclosed on a 'need to know' basis eg when I need to explain long absences, or get additional assistance, or when untrue rumours start to be passed around about why I am absent." Sally

Students have tended to disclose only to people who they feel need to know about their mental health status. There appears to be two major times or situations when disclosure most often occurs. The first of these is when enrolling or applying to enrol. The question, 'Do you have a disability?' is asked on the

application and enrolment forms. We found only two students who responded actually disclosed on this form. Students believe that disclosure of disability on application forms will be used to discriminate against them during the selection process.

The other time when students tend to disclose is when they become ill or when the illness severely impacts upon their academic progress. There appears to be a link between the timing of the disclosure in order to access academic and personal support, and the student's knowledge of their illness. On the surface, it seems that many students disclose and register with disability support services in anticipation that they may have to use the service at some stage. Generally this has been a decision based on previous experience of extended illness which has impacted upon the student's ability to study.

Several students disclosed and registered with disability support services at the time when their illness got to the stage where it affected their study, for example during periods or bouts of severe depression where getting out of bed became a chore in itself. Sometimes registration (disclosure) was on the advice of an outside counsellor or practitioner. On the whole, all decisions regarding when and to whom to disclose were decisions not taken lightly.

The issue regarding to whom and when to disclose is more complex when attempting to understand the individual student's own perception of mental illness and how that affects the way they feel about themselves. What the narratives have revealed, is that the perception of mental illness and the perception of competence and control are linked in a way that affects decisions related to disclosure and to seeking support generally.

Super-student, guilt, non deservedness and the importance of competence

"...Another reason why I haven't disclosed to my current coursework educator – to do well academically when you have a mental illness is a great self esteem boost." Ingrid

Laziness and 'scamming' are the most often reported characteristics attributed to students with a mental illness by others (Condeluci 1996 pp 25-31).

The characterisation of mental illness into identifiable symptoms that have culturally negative connotations, that is; tiredness, disengagement, emotional lability or compulsive and fixated thoughts becomes somewhat of a double bind. Not only are the symptomatic characteristics of various mental illnesses negatively connoted, the same characteristics can be assumed to be innate to the person and thus mental illness is just a handy tag to excuse those 'weaknesses'.

The students who participated in our research reported incidences where their evidence of illness was dismissed by academic staff as if to say it was a convenient excuse for being tired (lazy), disengaged (not committed) and emotionally depressed (just emotional). Further problems can occur if the thought of disclosure becomes anxiety provoking in itself, which impacts on top of the particular difficulties the student may be experiencing at the time. Students also seem to appropriate some of these negative connotations as if to say, they really are just lazy and have an external locus of control.

Not surprisingly, the fear of this attribution of disingenuousness and lack of commitment results not only in the student's unwillingness to disclose, but also in the tendency to prove to other people that the opposite is true. They are out to prove to themselves and to other people that they are just as capable as anyone else and in many cases, even more so, encouraging them to achieve 'super student' status.

Some students implied that they felt that they did not deserve 'special consideration' and felt somewhat guilty when applying for it. This issue of non-deservedness and guilt may be the motivating factor behind the special focus on achievement and competence that many of the students talk about. One student, Penny went so far as to condemn other students who use their 'special consideration'. She saw it as a "cop out" and resented students who 'scam' or abuse the system. Penny believed that using any form of special consideration would not be a reflection of her real ability. Interestingly, more than half of the students who replied to our survey are completing or have completed Honours or Ph.D. level studies. We can only speculate about this but it does indicate a high achievement level in the sample.

Conclusion - The dilemma of disclosure

"Self disclosure has always been a sensitive issue for me. I want to be open, yet not judged by others. It's a risk I take, to be or not be accepted." Helen

The dilemma is evident in all of the narratives posted to us. There is a great deal of anxiety related to the requirement to disclose one's mental health status but the consequences of not disclosing are seen to be worse. There is also anxiety in not disclosing (Pennebaker 1995). The dilemma then is in whom to disclose to and under what circumstances. The risk is that you will be seen as lazy and manipulative and the irony is in the risk of seeing oneself in the same way. Damned if you do. Damned if you don't.

We cannot conclude that there is any one way to look at all of this. Each student reports different feelings, responses and experiences. What is definitely apparent however, is that negative attitudes and ignorance are still issues despite the years of educational promotion aimed at allaying some of the myths

and misconceptions surrounding mental illness. What is concerning is that some of the most learned people are the most deplete in attitude and knowledge.

We are still in the process of examining possible institutional constraints to disclosure and thus to the access of academic support services. A report on our findings and recommendations will follow. Our aim here was to examine the prevalence of mental illness within a tertiary education environment compared to the number of people utilising academic support services and to describe the themes around the issue of disclosure that were presented to us, as experienced by students with a mental illness. Clearly there are many questions that still need to be asked and areas that need to be explored, in order to determine how our tertiary institutions can better accommodate students with a mental illness.

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