Early Intervention in the Real World

Differential impact of current diagnosis and clinical stage on attendance at a youth mental health service

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Abstract

Aim: To examine whether clinical stage of illness and current diagnosis influence appointment behaviour in a specialized primary-level youth mental health service.

Methods: Factors associated with attendance at 8697 appointments made by 828 young people (females = 497) aged 12–25 years over a 1-year period were analysed.

Results: The number of appointments made did not correlate with the rates of attendance. However, those with more severe psychiatric morbidity made significantly more appointments and missed significantly more appointments than those with less severe presentations. Impaired social functioning was the best predictor of female attendance rates, whereas age and clinical stage of illness best predicted male attendance rates. Current diagnosis rather than functional impairment appeared to influence the level of input offered by clinicians.

Conclusions: Age, gender, severity of illness, functioning and psychological distress had differential associations with both planned treatment intensity and attendance rates. These differences are likely to have implications for service provision in this youth population.

Key words: adherence, appointment, clinical staging, mental health service, youth.

A major public health concern is the high prevalence of mental disorders in young people (from about 12 to 25 years), and it is estimated that 75% of all disorders begin during this post-pubertal developmental period.¹ Mental disorders affect as many as one in five young people in any given year¹ and yet only one-third of young people access health services.² The response across Australia to this challenge has been to develop a widely accessible primary-level youth mental health service known as ‘headspace’.³–⁶ These headspace centres attempt to create youth-sensitive services that minimize barriers to help seeking and maximize engagement with professional care,⁷ with similar early intervention (EI) services operating around the world.⁸,⁹ The challenge for these EI services is to provide appropriate levels of clinical input across the spectrum of mental ill health severity; from non-specific psychological distress/impairment, to mild DSM disorders and associated problems, to sub-threshold or emerging severe mental disorders (such as syndromal or subthreshold psychosis) and to established, but previously undertreated severe mental disorders.¹⁰–¹³

The services attempt to help young people with less well-defined problems for three main reasons. First, research suggests that the less specific clinical presentations are not necessarily mild and self-limiting and even brief, acute problems can cause significant levels of distress and functional disability.¹⁴–¹⁶ Second, these symptoms may be highly responsive to a range of interventions with low risk-to-benefit ratios such as psychological therapies.¹⁴–¹⁶ Third, in youth in the peak age range for the onset of severe mental disorders, the current clinical presentation (whether or not the symptoms meet diagnostic criteria for a specific disorder) may represent an early, less specific form (early stage) of...
Clinical staging and appointment behaviour

a potentially more debilitating mental disorder that becomes established over future years. Many clinicians and researchers involved with youth mental health services recognize that the presenting problem may show heterotypic continuity over time and that additional clinical characteristics may help identify individuals at above average risk for developing severe disorders at a later time. One of the best ways to describe these heterogeneous clinical presentations and possible illness trajectories is to use clinical staging models.\(^{11,15,17,18}\) When clinical staging is used alongside traditional diagnoses, the combination can offer an important refinement to the cross-sectional diagnostic classification and help to capture not simply where the individual is ‘now’ but also to give an indication of how the problems may evolve in the future.\(^{19,20}\) (Examples of this approach are given in Appendix I.)

In our previous work, we have examined the treatment interventions that may be useful in treating the early stages of mental disorders (described as stages 1a and 1b) that are below the threshold set for traditional diagnosis (usually regarded as stage 2 or above).\(^{29}\) However, another key issue that needs to be explored is whether young people with early stage disorders will engage with health care. In youth services across the world, missed appointments or complete dropout of care is a widely acknowledged clinical problem,\(^{21–24}\) with a range of direct and indirect costs.\(^{25}\) However, most of the research undertaken on engagement with services or treatments (e.g., appointment attendance or patterns of mediation adherence) has been conducted in secondary and tertiary psychiatric settings that provide input to older adults with established diagnoses (i.e., stages 2–4). Many of these studies suggest that individuals with certain illness or demographic features may be more at risk of treatment dropout than others. In a university hospital outpatient clinic for 12- to 20-year-olds, Chariatte et al.\(^ {26}\) showed that the risk of missing an appointment is greater for young adults than it is for adolescents, but only in men. Young adults (men in particular) have also been shown in both primary care and specialist mental health services to have poorer appointment adherence than older adults.\(^{21,25,27,28}\) In regard to illness factors, severity of illness has also been shown to have a variable impact on appointment adherence depending on the client group and the treatment setting. Both acute illness or mild symptoms and interpersonal distress have been shown to be associated with more missed appointments in adult outpatient settings.\(^ {25,27,28}\) In an early psychosis service, those with more severe illness at entry were less likely to drop out of care, with the authors postulating that the treatment team may increase their efforts to keep these young people in care.\(^ {20}\) Interestingly, those with enduring illnesses such as schizophrenia seem to be more likely to attend services\(^ {31}\) whereas those with unclear diagnoses are more likely to drop out of care.\(^ {25,32}\) In their review of the factors related to disengagement from mental health services, O’Brien et al.\(^ {33}\) point out that overall there is no clear association between illness severity and treatment dropout, and that this may be the result of service structures that encourage adherence and engagement for those clients with greater psychiatric severity.

Clearly, we cannot extrapolate directly from the extant literature to populations where all the clients are young and the majority do not have a stable specific diagnosis. However, this does not negate the need to understand the likely uptake of care and treatment, especially in a setting such as headspace, where a core principle is the creation of user-friendly services that also target these early stages of illness. The central aim of this paper is to determine the clinical and demographic factors that are related to appointment adherence and planned level of treatment intensity in young people at the early stages of illness. Given the gender effects found in other studies of appointment adherence, we additionally wanted to test for differences between males and females.

METHOD

Sample

With ethics approval (granted by the University of Sydney Human Ethics Board), we analysed the data collected about young people aged 12–25 years who attended headspace Campbelltown (an early intervention primary-level youth mental health service in outer metropolitan Sydney, Australia) during 2013. All cases included in the dataset had previously provided written informed consent for their de-identified clinical information to be used for research purposes (supplemented by parental consent in those aged 12–16 years).

Services at headspace Campbelltown are provided by a range of clinicians (psychiatrists, clinical psychologists, social workers, occupational therapists, mental health nurses, general practitioners and vocational/educational specialists) at no cost to the young person. The service covers a large geographical area and so young people often travelling significant distances to attend appointments. Young people typically self-refer, or are referred by their family, other health-care providers or school staff; and in essence, the service operates at the interface
between primary and secondary care. After attending for an initial assessment, the service utilizes automatic text message reminders for client appointments (sent 2 days before the scheduled appointment) for all individuals offered care and treatment.

**Procedures**

The following information from the client’s medical record was selected and entered into a study dataset: age, gender, post code (to allow estimation of distance travelled to appointments), the total number of appointments made with the service and the total number of appointments attended. From the attendance data, the following variables were computed:

- **Appointment Adherence**: this was operationalized as the percentage of appointments attended (calculated as the number of appointments attended divided by the number of appointments made).

- **Planned Treatment Intensity**: this was operationalized as the actual number of appointments scheduled, whether or not they were attended, as an indicator of the clinician’s desire to make a future treatment appointment, and the client’s willingness to make that appointment.

- **Psychological distress**: this was measured using the Kessler-10 questionnaire (K10) and social and occupational functioning was measured via the Social and Occupational Functioning Assessment Scale (SOFAS).

- **Psychiatric Severity**: as outlined in Appendix I, this term was operationalized as the combination of clinical stage 1a or 1b (as an indicator of specificity of symptoms and/or the potential illness trajectory) and the presence or absence of any symptoms or problems meeting criteria for a current DSM-IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition) diagnosis. Thus, we generated four subgroups: cases at stage 1a (less specificity) and no current DSM-IV diagnosis (1aNoDx); stage 1b, no current diagnosis (1bNoDx); stage 1a, current diagnosis present (1aDx); and stage 1b, current diagnosis present (1bDx).

**Statistical analyses**

Analysis was performed using SPSS 22.0, with statistical significance set at \( p < 0.05 \) for all analyses. Differences between groups across baseline demographic and clinical features such as age, gender and appointment data were assessed using independent samples \( t \)-tests and chi-squared tests. Correlations between these variables were computed using Pearson’s product moment partial correlations (\( r \)).

A **mancova** was used to determine the effect of psychiatric morbidity (clinical stage and current diagnosis) on both the total number of appointments offered and the rate of attendance, while controlling for age, gender, SOFAS and K10. Two separate multivariate analyses were conducted for males and females to determine the unique differences in outcomes across both genders. To examine attendance rate as a categorical variable, two attendance groups were created (low and high attendance; using the median attendance rate as the cut point) and chi-squared tests were undertaken. Lastly, **ancova** was used to examine the main effects and interactions between psychiatric morbidity and gender.

**RESULTS**

Of the 1194 clients who attended headspace **Campbelltown** in 2013, 75% \((N = 890)\) had provided written informed consent to have their de-identified clinical information used for research purposes. Of these, 62 were excluded from the analysis (because of missing data). For the whole sample, the mean age was 17.3 (SD = 3.1) and 40% were male. The mean distance from the client’s home to the centre was 11.6 km (range 0–108 km). With regard to clinical staging, 579 (69.9%) were assigned to stage 1a and 249 (30.1%) were assigned to stage 1b. Stage 1b patients were significantly older, had greater levels of psychological distress (K10) and poorer functioning (SOFAS). Seventy per cent of stage 1a patients made up to 10 appointments (50% up to six appointments), whereas 70% of stage 1b patients made up to 19 appointments (50% up to 12 appointments). Table 1 shows significant differences between the four psychiatric morbidity groups on age, psychological distress (K10), functioning (SOFAS), appointments made and appointments attended.

The majority of the sample \((n = 483, 58.3\%)\) did not have a current DSM diagnosis recorded. For those with symptoms that met criteria for a current diagnosis, the most common presentations were depression \((n = 118, 14.95\%)\), anxiety \((n = 79, 9.5\%)\) or adjustment disorders \((n = 55, 6.6\%)\).

**Engagement with services**

Overall, the number of appointments made was not correlated with the rate of attendance \((r = 0.05, p = 0.14)\). As shown in Table 2, age, psychological distress and functioning were all significantly correlated with attendance rate and appointments made. Gender was significantly correlated with appointments made, with men tending to make more
appointments ($r = -0.10, p < 0.01$). Distance was not significantly correlated with the number of appointments made, number of missed appointments or the rate of attendance.

To further explore the relationship between attendance rate and psychiatric severity, a two-way chi-squared analysis was conducted for both men and women. Table 1 shows that for females, there was no significant relationship between psychiatric severity and higher attendance rate ($\chi^2 [3, 496] = 6.40, p = 0.09$), whereas for males there was a significant relationship between psychiatric severity and higher attendance rate ($\chi^2 [3, 332] = 15.03, p = 0.002$).

**Appointment and attendance rate analysis for females**

There were significant multivariate main effects for age [$F(2, 482) = 3.41, p = 0.034$], psychological distress [$F(2, 482) = 3.26, p = 0.039$], functioning [$F(2, 482) = 3.67, p = 0.026$] and psychiatric severity [$F(6, 964) = 30.90, p < 0.000$] observed for females on scheduled appointments and attendance rate. For the number of appointments made (see Fig. 1), there were significant main effects in the univariate ANCOVA for the covariates of age [$F(1, 483) = 3.85, p = 0.050$] and psychological distress [$F(1, 483) = 4.50, p = 0.034$]. The main effect of psychiatric severity was also significant [$F(3, 483) = 67.32, p < 0.001$]. For the rate of attendance, there were significant main effects in the ANCOVA for covariate of functioning [$F(1, 483) = 5.10, p = 0.024$] only.
Pairwise comparisons among the psychiatric severity groups on the number of appointments made showed that all groups differed significantly from each other with the exception of the difference between stage 1a with no current diagnosis and stage 1b with no current diagnosis (1aNoDx-1bNoDx MDiff = −0.80, \( p = 0.540 \)).

Pairwise comparisons among the psychiatric severity groups on the attendance rate showed no significant differences between any of the groups. Figure 2 shows the differences in rate of attendance made for each of the groups by gender.

Appointment and attendance rate analysis for males

Significant multivariate main effects were observed for age \( F(2, 323) = 3.40, \ p = 0.035 \) and psychiatric severity \( F(6, 646) = 15.92, \ p < 0.000 \) for number of appointments made and attendance rate. There were significant main effects in the ANOVA for psychiatric severity on number of appointments \( F(3, 324) = 31.49, \ p < 0.001 \) and for age on attendance rate \( F(1, 324) = 6.63, \ p = 0.010 \). For number of appointments made (Fig. 1), there was only one significant main effect in the ANOVA for psychiatric severity \( F(3, 324) = 31.49, \ p < 0.001 \). For the rate of attendance, there were significant main effects in the ANOVA for age \( F(1, 324) = 6.63, \ p = 0.010 \) with the effect of psychiatric severity approaching significance \( F(3, 324) = 2.16, \ p = 0.091 \). To further analyse the effects of stage and current diagnosis on attendance rate, a \( 2 \times 2 \) (stage \( \times \) current diagnosis) ANCOVA was conducted. Only the main effect of stage \( F(1, 323) = 4.89, \ p = 0.028 \) was significant, with current diagnosis \( F(1, 323) = 0.68, \ p = 0.412 \) and the interaction between stage and current diagnosis \( F(2, 323) = 4.22, \ p = 0.516 \) not significant.

Pairwise comparisons among the psychiatric severity groups on the number of appointments made showed that all groups differed significantly from each other with the exception of the difference between stage 1b with no current diagnosis and stage 1a with a current diagnosis (mean difference −2.53, \( p = 0.095 \)). Pairwise comparisons among the psychiatric severity groups on the attendance rate showed significant differences between stage 1b with no current diagnosis and stage 1a with a current diagnosis (mean difference −0.106, \( p = 0.027 \)) and stage 1a with a current diagnosis and stage 1b with a current diagnosis (mean difference 0.094, \( p = 0.041 \)). No significant differences were observed for any of the other comparisons. Figure 2 shows the differences in rate of attendance made for each of the groups by gender.

DISCUSSION

Client appointment adherence is an important issue for health services given the broader economic, service-level and client implications of this phenomenon. In primary-level youth services where demand is high and resources are stretched, understanding the factors that influence engagement (as measured by appointment adherence) may help improve service efficiency and treatment outcomes. Previous studies across different service platforms with different populations have shown that this is a multifactorial issue with a variety of potential causes and mediators.

The current paper has shown that within these services, psychiatric severity is a strong predictor of both appointments made and appointment adherence, but that the effect is moderated by gender. The number of appointments made or scheduled is an aspect of the collaboratively planned treatment for a client. The study shows that treatment intensity is significantly influenced by psychiatric severity for both males and females in that those at higher clinical stages with a diagnosis had more appointments made. The exception for both genders was the number of appointments made for stage 1b young people with symptoms that did not meet diagnostic criteria for a current DSM disorder. This group has functioning and psychological distress scores that are equivalent to other clients identified as being at stage 1b who also had a current DSM diagnosis, and
yet the former had less than half the number of appointments scheduled. It seems that decisions about treatment planning may be influenced by the presence of more clear-cut cross-sectional symptom profiles than by either the potential illness trajectory or the level of psychological distress or impairment in functioning. The lack of a current DSM disorder for those at stage 1b was associated with this group receiving less care than indicated by the scale of their impairment. In a service setting where young people present with both full syndromal and sub-threshold disorders, this study demonstrates potential biases the clinicians may have toward providing more input to young people when the current diagnosis is clearer. This warrants further research.

Treatment adherence in this study was measured primarily via the rate of attendance against collaboratively made appointments. The study showed differential effects between men and women on the rate of attendance. For young women, functioning as opposed to clinical stage or current diagnosis affected rates of attendance. Young men on the other hand, had attendance rates that were influenced by age mediated by clinical stage and not by current diagnosis. Specifically, those at higher clinical stages (1b) showed significantly poorer rates of attendance than those at lower clinical stages (1a). Interestingly, for both males and females, rates of attendance were uncorrelated with the number of appointments made. These findings have a number of implications. First, it appears that attendance behaviour for young women does not appear to be driven by psychiatric severity. For young men, however, despite their collaboration with their clinicians regarding scheduling future appointments, their attendance behaviour seems to worsen as the severity of their illness increases. While this gender effect on the relationship between shared decision-making and treatment adherence is worthy of further study, greater service-level efforts at keeping young men at higher clinical stages who are most vulnerable to risks of illness progression and deterioration engaged in care are supported.

Some of the limitations of the current study include the lack of inclusion of other variables known or hypothesized to influence appointment adherence, such as the therapeutic relationship, the health beliefs of young clients and satisfaction with the care provided, among others noted. Although not the focus of the current study, the interaction between these variables and clinical stage in this population would be a worthy line of further inquiry given the well-documented importance of each of these factors in youth service delivery. Nevertheless, these variables were chosen based on what clinical and demographic information is routinely collected and relatively easy to obtain early in treatment, which may provide an opportunity for appointment adherence to be better predicted and proactively managed early in care for those who appear to be at great risk of appointment non-adherence. The use of data from a single service within a primary-level youth mental health setting also represents another limitation of the study. Further research could seek to replicate these findings in other similar services across the world.

It would seem that in spite of their clear need for treatment, poor appointment adherence for stage 1b clients without a current diagnosis, who quite often have ambiguous, sub-syndromal or attenuated diagnoses, is consistent with previous research showing similar relationships in clients who do not have clear diagnoses. The findings from this study coupled with our findings from previous research clearly demonstrate the vulnerability of this group of at-risk young people and support the implementation of service models designed to address the unique care needs of young people assigned to stage 1b.

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REFERENCES


**APPENDIX I**

As noted in the introduction, traditional diagnostic categories reflect the cross-sectional assessment of symptoms at the time of clinical presentation. However, this diagnosis rarely takes into account other clinical features or risk factors that may indicate the likely course of any future mental health problems, and many young people have problems that evolve over time and/or show heterotopic continuity. Refinements are often needed to enable communication about psychiatric severity in young people, and in this study we combine clinical diagnosis (presence or absence of symptoms meeting DSM diagnostic criteria) with the clinical stage of illness.

In mental health, clinical staging can identify where an individual is located on a continuum from an ‘at risk’, asymptomatic state (stage 0), to a presentation meeting the threshold for diagnosis (usually stage 2), through to end stage disease (stage 4). It is increasingly clear that many young people presenting to clinical services are located between stage 0 and stage 2 (i.e. stage 1a and stage 1b) and so they are the target of the present study. These cases are often characterized in the following way. First, young people may have symptoms that lack specificity for a particular diagnosis and/or that fall below the traditional threshold set to make a definitive diagnosis. These individuals would typically be
regarded as at stage 1a (non-specific but distressing symptoms). Second, they may have symptoms that meet current diagnostic criteria for a high prevalence disorder (such as anxiety or depression), but they may have other characteristics that identify them as being at ultra-high risk for the development of psychosis or bipolar disorder. For example, with regard to the latter, they may present with depression in the context of cyclothymic personality and a family history of bipolar disorders. While these individuals would be classified as having a current DSM diagnosis of major depressive disorders, they would also be regarded as being at clinical stage 1b. The latter classification indicates that there is an above average possibility that the future illness trajectory will follow a bipolar course, but that the individual does not currently have symptoms of bipolar disorder that meet the established diagnostic criteria (stage 2). In clinical practice, stage of illness, especially for cases between stage 0 and stage 2, is determined at a consensus clinical review team meeting using criteria set forth in Appendix I of the paper published by Hickie et al.\textsuperscript{11}