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Protocol: A Grounded Theory of 'Recovery'- Adolescent Service Users' Perspectives

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ABSTRACT

Introduction: Policies internationally endorse the recovery paradigm as the appropriate foundation for youth mental health services. Grounded in the views of adults who have experienced severe and enduring mental illness, the recovery paradigm's applicability to young people is uncertain, and the voices of young people are under-represented in discussions of recovery. A comprehensive understanding of the experiences and expectations of young people is critical to developing youth mental health services that are acceptable, accessible and relevant to the people they seek to support.

Aim: To inform development of policy and services, the study described in this protocol aims to develop a comprehensive explanation of adolescents' experiences and expectations when they encounter mental health challenges, and as they transition through child and youth mental health services. The study will conceptualise and model recovery from the adolescents' perspective.

Method and Analysis: Quantitative and qualitative data for this grounded theory study are being collected in interviews from adolescents aged 12-17 years engaged with Child/Youth Mental Health Service in Queensland Australia. The study explores adolescents' experiences of mental health challenges, their expectations and experiences as they transition into and through mental health services, the meaning of their experiences and ideas of 'recovery', and how their experiences and expectations are shaped. Data collection and analysis will use grounded theory methods.

Ethics and dissemination: Adolescents' experiences will be presented as a mid-range theory. The research will provide tangible recommendations for youth-focused mental health policy and practice. Findings will be disseminated within academic literature and beyond to participants, health professionals, mental health advocacy groups, and policy and decision makers via publications, research summaries, conferences and workshops targeting different audiences. Ethical and research governance approvals have been obtained from relevant Human Research Ethics Committees and all sites involved.

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Strengths and limitations:

- This protocol outlines a study that offers an in-depth, longitudinal exploration of adolescent service-users' experiences and expectations of recovery as they experience mental disorders.
- The study design enables generation of a theoretical explanation of adolescents' journeys through mental health challenges and service encounters.
- The theory developed in the study will be generated on the basis of select experiences of a particular sample, within a particular socio-political context, and it is acknowledged that others may have differing experiences. However, this is balanced by acknowledgement that the theory is partial and grounded in the data documenting young people's own perspectives relating to recovery and care needs.
- The study will contribute to the limited literature giving voice to young people's perspectives on recovery, and will contribute to a much needed conversation which could inform recommendations for service development.

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INTRODUCTION

Adolescence is a period of multiple transitions integral to formation of identity and finding a place in the world.[1 2] The majority of adolescents negotiate these typically tumultuous times successfully.[3] A substantial minority, however, experience cognitive, affective and behavioural disturbances, some meeting diagnostic criteria for a mental disorder. While prevalence rates vary, mental disorders amongst young people are acknowledged as a global phenomenon affecting up to 25% of adolescents in Australia and the UK.[4 5] Disruptive to normal developmental processes and associated with risk taking behaviour, mental disorders emerging in adolescence affect personal and social development and educational and occupational opportunities. Frequently continue into or recurring in adult life, mental disorder in adolescence has long term negative impacts on health, educational, economic and social outcomes.[6]

With mental disorders contributing more than 60% of the total burden of health-related disability for 15-34 year olds,[4] promoting mental health and ensuring timely treatment of mental disorders is a priority in Western countries. While evidence supports the effectiveness of a range of pharmacological and psychosocial interventions in improving outcomes,[5] young people experiencing mental disorders commonly fail to access professional help or specialist services.[7-9] When they do, engagement is often tenuous, and early disengagement rates are high.[10]

Improving services is recognised as an economic, moral and social imperative. Across the 'wealthy West', reform of mental health services for both adults and young people is predicated on the 'recovery' paradigm.[11-14] This paradigm is grounded in the view that people experiencing mental disorders are capable of living "full, satisfying, hopeful and contributing lives…" even if "the illness is not 'cured'".[15(p15)] Conceptualised not as an event or endpoint but as a 'journey',[16] personal recovery is differentiated from clinical recovery defined as symptom remission or functional restoration. Recovery is regarded as a process of restoring connectedness, hope, identity, meaning and empowerment.[17] Services adopting a recovery paradigm recognise the person receiving treatment as an expert in relation to themselves and their care needs, and capable of setting personal and health-related goals. Such services promote shared decision making and self-determination

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while encouraging development of an identity as a person living with, but not defined by, mental health experiences.[18] While intuitively attractive, the recovery model has been developed by adults, for adults, based on adults' experiences of severe, complex and enduring mental illness.

With only around one third of adolescents experiencing mental disorder accessing formal services,[7] research has focused to date on factors influencing access and engagement. Studies are consistent internationally in locating challenges in mental health literacy, stigma, discomfort with professional help or help-settings, and limited resources with which to access services.[7 10 19 20] Little is known, however, about adolescents' expectations or experience of services. Their views about 'recovery' remain uncertain but the limited evidence available suggests that it is inconsistent with the prevailing recovery paradigm. A seminal study by Simonds and colleagues[21] in regard to adolescents' recovery processes identifies that their expectations largely align with notions of 'clinical' recovery, grounded in the elimination of symptoms to restore a 'normal life', however that may be defined. Furthermore, indicating limited acknowledgement of autonomous personal effort, adolescents attribute symptom remission to time and maturation or alternatively medical and psychiatric intervention. This contrasts substantially with the adult recovery paradigm's emphasis on self-determination.

If youth mental health services are to be person centred and effective, it is critical that their development be grounded in detailed understanding of the views of young people. Knowing what young people expect and experience, and how they define recovery, is essential to implementation of recovery-oriented practice in developmentally and contextually appropriate ways. Further research is required to understand how adolescents experience mental health challenges over time, how they make sense of and negotiate concerns, what supports they seek, if any, and the events, actions and conditions that shape their trajectories.

Aims and objectives

To inform mental health policy and service development, this study aims to develop a comprehensive contextualised explanation of adolescents' experiences as they encounter mental health difficulties and enter and transition through mental health services (hereafter referred to as their 'journey').

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Objectives: (1) Qualitatively map participants' journeys; (2) Identify critical moments within these journeys; (3) Identify contextual and personal influences shaping the journeys and their impacts; (4) Describe interconnections among networks of critical moments; and (5) conceptually model the adolescent journey and 'recovery'.

METHODS AND ANALYSIS

Paradigm and methodology

This study employs a grounded theory (GT) methodology. Developed by sociologists Glaser and Strauss[22], GT is widely used in health and social sciences to generate theoretical accounts of social phenomena. Described as the "the most comprehensive qualitative research methodology available",[23(p1)] GT is appropriate when research aims to explain a process, where the concerns of those involved are central to its understanding and cannot be predetermined.[22 24]

GT methodology is distinguished by its core strategies: recursive study design, theoretical sampling, and constant comparative system of analysis.[25] In GT, data collection and analysis occur iteratively, the results of one cycle informing the next. Throughout this process, data sets are constantly compared with each other and against developing conceptualisations to generate successively more abstract concepts. Sampling proceeds on theoretical grounds whereby hypotheses generated from the data guide further data sampling for ongoing theory refinement. Theoretical sampling typically continues to 'saturation', the point at which further data collection provides no new information for theory development.[22] Theories thus 'grounded' in the data and are 'mid-range' in that they lie between hypothetical statements dealing with narrowly defined phenomena, and highly abstract, all-encompassing 'grand' theories.[26]

GT methodology has 'evolved' since its initial description such that there are now several recognised variants.[27] While core features are retained, different versions reflect the world views of their proponents and adopt differing positions in relation to timing in the use of literature, the researchers' role and specific analytical techniques. This study employs the approach described by Corbin and Strauss [27] within a pragmatic paradigm developed by Rorty.[28] Consistent with the tenet of pragmatic

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epistemology, that there are no fixed points from which reality can be observed, researchers and participants are understood as interactively constructing knowledge during the research process.[27 29] Resultant theory acknowledges "temporal, cultural and structural context" [29(p524)] and conditions that give rise to the studied phenomenon. The theory is understood as provisional, its value dependent on its relevance to real world problems and capacity to support change.

Study team

The study team comprises an early career researcher (Author 1) and three experienced clinician-researchers with complementary expertise in the topic and methodology. The study is being coordinated by Author 1 (hereafter 'researcher'), a PhD candidate and registered psychologist with 14 years' experience working clinically within specialist youth mental health services. Authors 3 and 4 are experienced academics with backgrounds in clinical and educational/ developmental psychology. Author 2, also trained as a psychologist, is a health services researcher with substantial qualitative research experience.

Study setting

This study is being conducted in Queensland, Australia with participants recruited from specialised Child and Youth Mental Health Services (CYMHS). CYMHS, funded by the Queensland Government, provide specialist assessment and treatment for young people (<18 years) experiencing severe or complex mental health conditions. While local socio-economic and demographic characteristics, and availability of other services influence eligibility criteria, CYMHS typically offer services to young people experiencing substantial distress and disruption in daily functioning. Assessment and interventions, including individual and family psychotherapy, are provided by medical, nursing and allied health professionals working in multi-disciplinary teams. Consistent with national and state 'recovery oriented' policy, CYMHS operate on the premise that young people can, and do recover from mental disorders.[30]

Participants and recruitment

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Participants are adolescents attending CYMHS across four study sites selected to represent geographic (regional/rural/inner city), socio-economic and cultural variation. Eligibility criteria (see table 1) are intentionally broad to promote recruitment of a sample with varied experiences.

While sample size in GT is determined on the basis of credibility in context of the purpose of the inquiry,[31] practicalities and time require an estimation. Based on team members' experiences and Cresswell's[26] recommendations for achievement of saturation, we aim to recruit 30 participants. Recruitment commenced in July 2015 and will continue until 30 participants are recruited or until January 2017. At the time of writing, 17 participants have been recruited.

Table 1 Eligibility criteria for CYMH service users
Inclusion criteria
• aged 12 to 17 years, inclusive
• engaged with CYMHS for up to 3 months in current service episode
• diagnosed with a mental disorder representative of those typically treated at CYMHS
• Children's Global Assessment Scale (CGAS) score of 70 or less
• clinically assessed as having adequate psychiatric and cognitive capacity for study participation
• sufficiently conversant in the English language to complete interview
Exclusion criteria
• consumers with neurodevelopmental, organic and brain injury diagnoses or impairments

In collaboration with identified site contacts, recruitment follows procedures set out in figure 1.

Data collection

GT is a flexible methodology[27] that does not delimit the types of data acquired, the techniques of collection or the way they are used. Indeed use of different kinds of data is recommended, also providing alternate vantage points on the phenomenon.[22] In this study, primary data are participants' first person accounts, supplemented by two quantitative measures of mental health. Data are collected in semi-structured interviews conducted at two time points, first at recruitment and then three to six months later, depending on participants' availability and engagement with CYMHS. Interviews are conducted by the researcher in private rooms at CYMHS, educational or community services

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facilities. A conversational approach is used with the researcher following leads in participants' accounts, and using participants' language to encourage articulation of experiences and views.

Data collection is supported by the flexible use of a topic guide (summarised in table 2). The topic guide was informed by a review of literature related to adolescents' and young adults' experiences of 'recovery',[21 32] interviewing young people,[33 34] interviewing forGT,[24 35] and the study team's clinical and research experiences with young people. Two visual aids, employed at participants' discretion, are used to support description and critical reflection on experiences. First, early in bothi nterviews, participants are invited to complete a timeline[36] of their 'journey' to date, from awareness of difficulties to first interview, then from initial interview to the second. As timelines are constructed, participants are prompted to identify and explore personally significant events and feelings associated with these events. Second, a set of cards called 'ups and downs'[37] is available to support expression of feelings and description of experiences. Depicting a figure experiencing diverse emotions while floating at sea, the cards are used in conjunction with the timeline or separately.

The topic guide and use of the timeline were piloted with two young people (known to members of the study team) who had experienced sub-clinical mental health problems. When de-briefed and invited to critique the interview, these young people reported finding the interview experience enjoyable and an opportunity to learn about themselves. No changes to the topic guide or interview process were recommended.

Table 2 Initial interview topic guide domains
Recognising and experiencing onset of mental health challenges
• When, how, what difficulties came to awareness (commence timeline)
• Understandings of causes, meanings attributed
• How the problems impacted them at home, school, community, relationships and vice-versa
Initial actions, disclosures or noticing
• Others' noticing - when, how, their actions/ responses and what this meant to participant
• Participant's actions, disclosures – how, when, responses by others, what this meant
• What happened next? (continue timeline)
Timing/ Decisions regarding accessing support
• When, how, by whom decisions were made about getting professional help
• What led to the decisions being made, and what other alternatives were considered
• Initial feelings about these decisions - concerns, expectations associated with seeking support
Engagement with services
• Experience of accessing / engaging with services, where, when, why those
• Experience of initial processes – helpful/ unhelpful processes or experiences

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- Suggestions for improvement

Expectations

- Expectations and hopes regarding the difficulties, what might help
- Perception of others' expectations, personal reactions/responses to these
- Expectations of the future

Change

- Perceived changes to date (if any) - how, when, under what conditions, in what contexts (home, school, neighbourhood, relationships)
- Perceived cause of changes (if any)
- Personal actions contributing to changes (if any)
- Effect of changes on self and relationships across home, school, neighbourhood settings

Other Pertinent Issues

- Invitation to add other important ideas, experiences

To provide clinical context to participants' journeys, participants are invited to complete two self-report measures either at the start or end of each interview. The measures are the Strengths & Difficulties Questionnaire (SDQ),[38] and the Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS).[39] The SDQ, selected because it is routinely used within CYMHS, measures psychosocial difficulties, pro-social function and impact. Completion involves rating the extent to which 25 attributes are 'true' for the participant on a three-point scale ('not', 'somewhat' or 'certainly'). Designed for 4–16 year olds but validated for use to age 19, the SDQ has a reported Cronbach's alpha of 0.82 for a score of total difficulties, demonstrating satisfactory internal reliability. The BMSLSS,[39] selected to provide an indication of wellbeing and treatment progress, generates a single 'satisfaction' score on a continuous scale of 1 to 5 within each of five dimensions (family, friendship, school/work, self, and living environment). Scores are summed to calculate overall life satisfaction. The BMSLSS demonstrates satisfactory psychometric qualities with Cronbach's $\alpha = 0.76$ to 0.85 in normative samples[40] and $\alpha = 0.77$ for an 11-17 year old clinical sample[41].

Additionally, participants' scores on the SDQ routinely collected by CYMHS clinicians at treatment commencement are being obtained from clinicians, with participant consent.

Interviews last around 90 minutes and are audio recorded with permission. Following each interview, participants are offered a $25 gift voucher in recognition of their contribution.

Data management and analysis

Dependent on type, data are managed and analysed using SPSS Version 22 or NViVo10.

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Following each interview, quantitative data are entered into SPSS.[42] Scores are calculated according to instrument guidelines. Upon completion and scoring of the second time-point measures, each participant's scores will be compared to identify clinical and reliable change. Results are categorically described (e.g. 'no change', 'clinical and reliable change') and combined with participants' second time-point qualitative information.

Interviews are transcribed verbatim. Along with timelines and notations about which picture cards are used, transcripts are uploaded to NViVo10[43] for storage and management. Prior to formal coding, each transcript is carefully read to identify chronology of events and the important aspects related to them. A chronological summary of each case is made to keep track of each participant's progressive journey during the analytic process.

As described by Corbin and Strauss,[27] the process of analysis involves deconstructing, conceptualising and creatively reconstructing data in new ways, enabling development of new theories. Analyses in this study involves six iterative stages: (1) Within case analyses incorporating quantitative measures at time point 1; (2) Cross case comparisons at time point 1; (3) Within case analyses at time point 2; (4) Cross case comparisons at time point 2; (5) Within case analyses across time points incorporating clinical indicators of change and chronology; (6) Cross case comparisons across time. Analysis at each stage, involves systematic coding and constant comparative methods. Each transcript is segmented into units of meaning which are labelled descriptively. The concepts thus formed are examined in relation to each other, with similar concepts categorised according to more abstract themes and labelled to reflect their similarity. Subsequent interviews are coded with early codes in mind, and similar concepts are coded in a similar manner. Comparisons between concepts and categories are made within and between cases, codes either added to existing categories or new categories developed. As interviews progress, the dimensions and properties of each category are established such that distinct, richly described 'saturated' categories are formed. Theory building then commences, moving from inductive interpretation of the data to reasoned analysis of how the categories relate.

Theory development

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The storyline approach described by Strauss and Corbin is being used to construct and convey "a descriptive narrative about the central phenomenon".[44(p116)] The first step in theory building involves linking progressively developing categories chronologically and conceptually to form a storyline. Supporting theory formation, propositional statements made in relation to how categories relate, within which contexts, under what conditions and with what results (in context C, process A occurs resulting in experience B). Saturated categories are further examined to develop an understanding of the most salient issues and to identify a 'core' category or central storyline to which all other categories relate. Finally, the theory is situated contextually and boundaries are established. The process of theory development is regarded as complete when the conceptual framework forms a systematic theory reasonably represents, in a manner appropriate to use, the phenomenon of interest.

Rigour in analysis

Because qualitative research is inherently subjective,[45] the researchers' wise judgement and diligence are central to the integrity of the product.[46] Credibility relies on presentation of analysis such that the reader is persuaded of "the plausibility of interpretations".[47(p204)] Rigour in GT involves ensuring adequacy and trustworthiness of the theory. In this study, rigour will be promoted in three interlinked ways: audit trail, critical dialogue amongst authors, and checking understanding with participants as the theory develops. First, to enable others to follow the process of analysis, procedural and analytical decisions are documented, including theoretical sampling decisions and progression, challenges to and resolution of hypothetical formulations.[48] Second, the analytical process is being supported by ongoing dialogue between co-researchers who meet approximately monthly during the data collection and analysis phases of the research with Co-researchers acting as critical friends, challenging the researcher to justify coding and analysis with reference to data and testing alternative explanations.[48] Corbin & Strauss [49] suggest this 'opening up' of analyses for peer scrutiny helps guard against bias by promoting reflexivity. Third, 'reflexivity', self-awareness or thought about how the research process and its outcomes are influenced by the researcher,[50] is further promoted by keeping a record of the researcher's thoughts, reactions and feelings during data collection and analysis. This self-reflection process assists in identifying assumptions and biases, and provides

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opportunities to revise research questions and maintain openness to other possible interpretations of the data.

Quality of the theory

There is consensus amongst proponents of GT that quality of the theory is first and foremost dependent on it being grounded in the data.[22 24 35] Dependent on approach and purpose, various other properties have been recommended as characterising a good theory. In this study, quality of the theory will be assessed on the basis of fit, relevance and workability of the theory,[22] and given the pragmatic approach, its usefulness.[24] 'Fit' is evidenced when categories and concepts relate to the data. Assessment of fit will be enabled by presenting data excerpts to illustrate concepts. Relevance relates to the resonance of the theory[24]– the extent to which it 'rings true' to participants and/or others who share their circumstances, eliciting an emotional response.[51] A workable theory explains and interprets what is happening in the process under investigation, accounting for any variation.[22] To enable assessment of workability, the storyline will be presented in diagrammatic and narrative form. Explanation of the storyline will include description of the contexts and conditions within which events, actions or interactions occur. It will also describe the manner in which they vary, under which circumstances, and with what consequences. Pragmatically, the 'usefulness' of the theory should be assessed in relation to its applicability, its suitability as a basis for making recommendations within every day settings, and for generating discussion and further research.[24] Assessment of the theory's usefulness will be aided by outlining limitations of the study and recommendations for future research. Recommendations for policy and practice will also be made.

ETHICS& DISSEMINATION

Ethical considerations associated with this research

Researchers, whatever the field are obliged to balance participants' rights against risks in research participation. Children and adolescents have the right to express their views on matters of relevance to them,[52] and one way of doing this is through research participation. To promote young people's right to consider participation in this study, (1) young people have direct access to age-appropriate research flyers and pamphlets via displays in service reception areas, (2) the researcher is working

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proactively with clinicians involved in recruiting to identify eligible service users, and (3) clinicians are encouraged to consider potential participant's rights and autonomy to consider research participation, and thus not make decisions for the young person, for example regarding their interest in the study.

Well established protocols describe processes and procedures to minimise risks in research participation for children, and for people who experience mental disorders[53]. To maintain rights to privacy, the first approach to potential participants is made by clinicians already involved with their care. While clinicians are encouraged to ask all eligible service users whether they will meet with the researcher, clinicians consider the potential impact of research participation and assesses the potential participant as capable clinically and emotionally of understanding and taking part in the study. Upon referral, research purposes and procedures are explained in age-appropriate language. The voluntary nature of the study and participants' right to withdraw without consequence are emphasised. Confidentiality and limitations to confidentiality are discussed with a particular focus on duty of care and management of privacy - secure storage of information, and participants' anonymity in presentation of results. Before inviting participation, potential participants are asked to describe in their own words what they are being asked to do and for what purpose. Participants provide consent in their own right, and co-consent is sought from parents/carers or other responsible adults familiar with the young person. During data collection, various strategies are employed to minimise power differentials. The researcher maintains a focus on participants as experts in themselves and uses age-acceptable interviewing techniques and processes. Participants may, at their discretion, invite a support person to accompany them during the interview, on the understanding that the researcher will not be asking questions of the support person.

It is possible that participants may experience emotional discomfort in the process of sharing personal stories. Should participants appear distressed, they are encouraged to take breaks or terminate the interview. If participants disclose risk of harm to self or others, duty of care in the best interest of the young person takes precedence in line with the relevant professional code of ethics,[54] and issues of risk are referred, in consultation with the young person, to their clinician or carer.

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Participants expressing concerns about their mental wellbeing are referred to their treating team. A document detailing local, on-line and telephone mental health support options is also provided.

Dissemination of Research Results

The research will be reported as a PhD thesis and in various other formats and settings. The thesis will be made available online through the University library, and results also disseminated via workshops, within clinical peer/ student supervision forums, as summary reports to participating research sites, conference presentations and published articles. Participants will be offered a summary of research findings or links to publications. Research groups and Consumer-Carer Advocacy Groups within participating districts will be offered a copy of relevant publications.

When reporting the study processes and findings, the 32-item consolidated criteria for reporting qualitative research (COREQ)[55] checklist will be used to address three domains relating to research team and reflexivity, study design, and data analysis and reporting.

DISCUSSION

To our knowledge, this is the first longitudinal qualitative study, and the first using grounded theory methodology, to deliver a comprehensive theoretical explanation of adolescent recovery. The theory developed in this study will be generated on the basis of select experiences of a particular sample, within a particular socio-political context, and it is acknowledged that others may have differing experiences. However, this is balanced by the acknowledgement that the theory is partial and grounded in the data documenting young people's own perspectives relating to recovery and care needs. The theory will contribute to a much needed conversation, and in line with a pragmatic foundation, could inform recommendations for government and non-government, health, educational and research organisations regarding (1) the planning and delivery of care and support for adolescents in ways that are right for them, (2) development of age-appropriate recovery measures, and (3) future research with adolescents experiencing mental health challenges. Our aspiration is that it will improve the capacity of care providers to recognise and respond to the needs of young people in a timely and effective manner.

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Contributors All authors were responsible for the development and refinement of the protocol. LP wrote the draft and final manuscripts. SP provided substantial intellectual input into informing methodology and provided overall review of structure. GB and AO contributed to critical review, editing and final approval of the version to be published.

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Competing interests None

Ethics approval This study has been reviewed and approved by the National Health and Medical Research Council authorised Human Research Ethics Committees of Mater Health Services (Ref. HREC/14/MHS/208) and Griffith University Research (Ref PSY/26/15/HREC). Governance approvals have been obtained from each site.

Figure Legend

Figure 1: Recruitment Process

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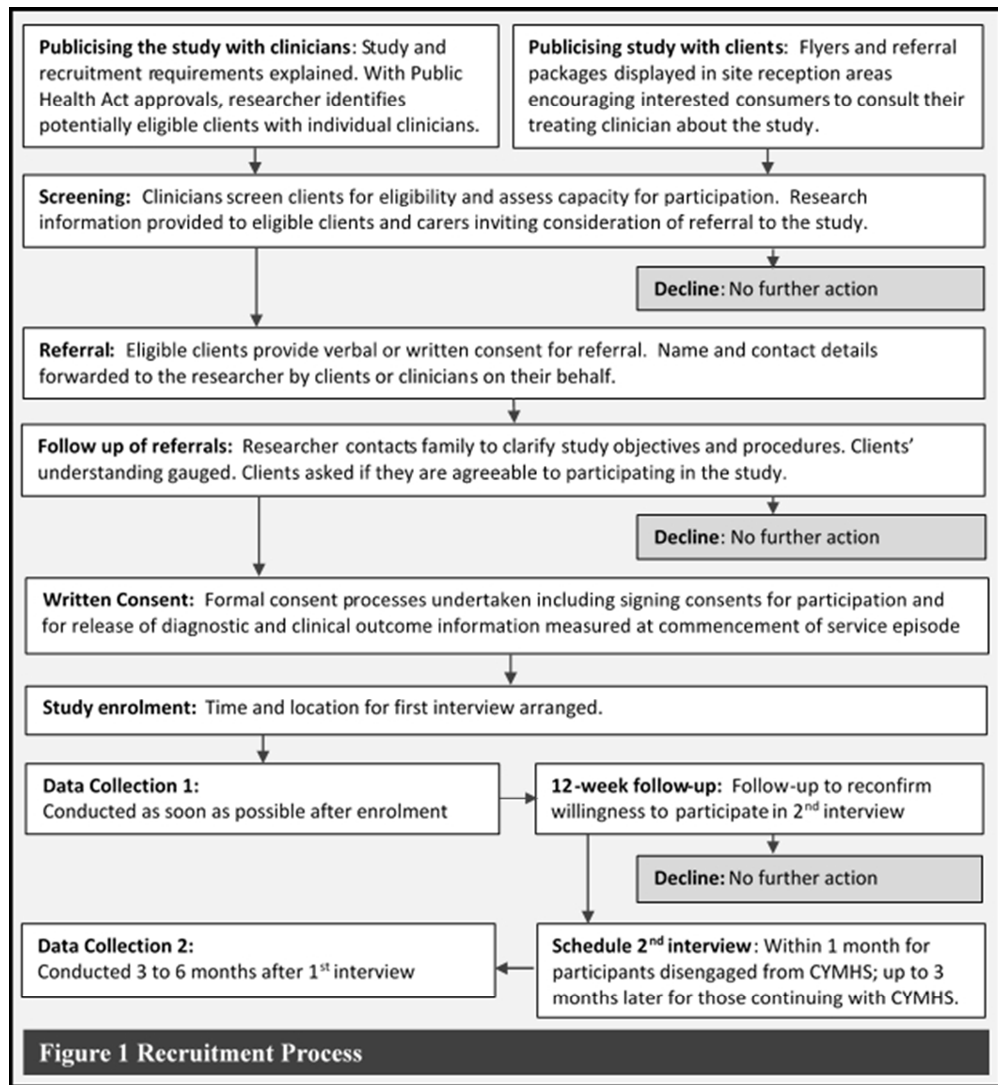

Figure 1 Recruitment Process

165x179mm (96 x 96 DPI)

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Protocol: A grounded theory of 'recovery' - adolescent service users' perspectives

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Protocol: A Grounded Theory of 'Recovery'- Adolescent Service Users' Perspectives

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ABSTRACT

Introduction: Policies internationally endorse the recovery paradigm as the appropriate foundation for youth mental health services. However, given this paradigm is grounded in the views of adults with severe mental illness, applicability to youth services and relevance to young people is uncertain, particularly as little is known about young people's views. A comprehensive understanding of the experiences and expectations of young people is critical to developing youth mental health services that are acceptable, accessible, effective and relevant.

Aim: To inform development of policy and youth services, the study described in this protocol aims to develop a comprehensive account of the experiences and expectations of 12-17 year olds as they encounter mental disorders, and transition through specialist mental health services. Data will be analysed to model recovery from the adolescents' perspective.

Method and Analysis: This grounded theory study will use quantitative and qualitative data collected in interviews with 12-17 year olds engaged with specialist Child/Youth Mental Health Service in Queensland, Australia. Interviews will explore adolescents' expectations and experiences of mental disorder, and of services, as they transition through specialist mental health services, including the meaning of their experiences and ideas of 'recovery', and how their experiences and expectations are shaped. Data collection and analysis will use grounded theory methods.

Ethics and dissemination: Adolescents' experiences will be presented as a mid-range theory. The research will provide tangible recommendations for youth-focused mental health policy and practice. Findings will be disseminated within academic literature and beyond to participants, health professionals, mental health advocacy groups, and policy and decision makers via publications, research summaries, conferences and workshops targeting different audiences. Ethical and research governance approvals have been obtained from relevant Human Research Ethics Committees and all sites involved.

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Strengths and limitations:

- This protocol outlines a grounded theory study of adolescent service-users' experiences and expectations as they encounter mental disorders and transition through mental health services.
- The study will support conceptualisation and a theoretical explanation of adolescents' journeys through their experiences of mental disorder and service encounters.
- The theory developed in the study will be generated on the basis of select experiences of a particular sample, within a particular socio-political context, and it is acknowledged that others may have differing experiences. However, this is balanced by acknowledgement that the theory is partial and grounded in the data documenting adolescents' own perspectives relating to recovery and care needs.
- The study will contribute to currently limited literature, giving adolescents a voice in discussion of experiences and perspectives on recovery, and will contribute to a much needed conversation which could inform recommendations for service development.

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INTRODUCTION

Adolescence is a period of multiple transitions integral to identity formation and finding a place in the world.[1 2] These often tumultuous times are negotiated successfully by most adolescents.[3] A substantial minority, however, experience cognitive, affective and behavioural disturbances, some meeting diagnostic criteria for a 'mental disorder'. While prevalence rates vary, mental disorders amongst young people are acknowledged as a global phenomenon, affecting up to 25% of adolescents in Australia and the UK.[4 5] Disruptive to personal and social development and associated with risk taking behaviour, mental disorders in adolescence frequently continue into or recur in adulthood impacting educational and occupational opportunities, with potential long term consequences for health, economic and social outcomes,[6] and quality of life.[7 8]

With mental disorders contributing more than 60% of the total burden of health-related disability for 15-34 year olds,[4] promoting mental health and ensuring timely treatment is a priority in Western countries. While evidence supports the effectiveness of various pharmacological and psychosocial interventions in improving outcomes,[5] young people experiencing mental disorders often do not access professional help or specialist services.[9-11] When they do, engagement is often tenuous, and early disengagement rates are high.[12]

Improving services is recognised as an economic, moral and social imperative. Across the 'wealthy West', reform of mental health services for both adults and young people is predicated on the 'recovery' paradigm.[13-16] This paradigm is grounded in the view that people experiencing mental disorders are capable of living "full, satisfying, hopeful and contributing lives…" even if "the illness is not 'cured'".[17(p15)] Conceptualised not as an event or endpoint but as a 'journey',[18] personal recovery is differentiated from clinical recovery defined as symptom remission or functional restoration. Recovery is conceptualised as a process of restoring connectedness, hope, identity, meaning and empowerment.[19] Services adopting a recovery paradigm recognise the person receiving treatment as an expert in relation to themselves and their care needs, and capable of setting personal and health-related goals. Such services promote shared decision making and self-determination while encouraging development of an identity as a person living with, but not defined by, mental

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health experiences.[20] While intuitively attractive, applicability to young people of the recovery model, developed by adults for adults, is uncertain.

With only around one third of adolescents experiencing mental disorder accessing formal services,[9] research to date has focused on factors influencing access and engagement. Studies are consistent internationally in locating barriers to access in mental health literacy, stigma, discomfort with professional help or help-settings, and limited resources with which to access services.[9 12 21 22] Little is known, however, about adolescents' expectations or experience of services. Their views about 'recovery' remain uncertain but the limited evidence available suggests they may be inconsistent with the prevailing recovery paradigm. A seminal study by Simonds and colleagues[23] in regard to adolescents' recovery processes identifies that their expectations largely align with notions of 'clinical' recovery, grounded in the elimination of symptoms to restore a 'normal life', however that may be defined. Furthermore, indicating limited acknowledgement of autonomous personal effort, adolescents attribute symptom remission to time, maturation or alternatively medical and psychiatric intervention. This contrasts substantially with the adult recovery paradigm's emphasis on self-determination.

If mental health services for adolescents are to be acceptable and effective, it is critical that service development be grounded in detailed understanding of service-users' experiences and expectations. Knowing how adolescents define and experience recovery is essential to implementation of recovery-oriented practice in developmentally and contextually appropriate ways. Further research is required to understand adolescents' experience of onset and progression of mental disorders over time, how they make sense of and negotiate concerns, what supports they seek, if any, and the events, actions and conditions that shape their trajectories.

Aims and objectives

This study aims to develop a comprehensive contextualised explanation of adolescents' experiences as they encounter onset and progression of mental disorder and transition into and through mental health services (hereafter their 'journey').

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Objectives: (1) Qualitatively map participants' journeys; (2) Identify critical moments (e.g. turning-points, decisions, actions) within these journeys; (3) Describe relationships among networks of critical moments; (4) Identify contextual and personal influences shaping the journeys; (5) conceptually model the journey and 'recovery' including the core process and critical moments involved in the journey.

METHODS AND ANALYSIS

Paradigm and methodology

This study employs a grounded theory (GT) methodology. Developed by sociologists Glaser and Strauss[24], GT is widely used in health and social sciences to generate theoretical accounts of social phenomena. Described as the "the most comprehensive qualitative research methodology available",[25(p1)] GT is appropriate when research aims to explain a process where the concerns of those involved are central to its understanding and cannot be predetermined.[24 26]

GT methodology is distinguished by its core strategies: recursive study design, theoretical sampling, and constant comparative system of analysis.[27] Data collection and analysis occur iteratively, results of one cycle informing the next. Throughout this process, data sets are constantly compared with each other and against developing conceptualisations to generate successively more abstract concepts. Sampling proceeds on theoretical grounds whereby hypotheses generated from data guide further data sampling for theory refinement. Theoretical sampling continues to 'saturation', the point at which further data collection provides no new information for theory development.[24] Theories thus 'grounded' in data and are 'mid-range', lying between hypothetical statements about narrowly defined phenomena, and highly abstract, all-encompassing 'grand' theories.[28]

GT methodology has 'evolved' since its initial description. There are now several variants.[29] While core features are retained, different versions reflect their proponents' world views and adopt differing positions related to timing in the use of literature, the researchers' role and specific analytical techniques. This study employs Corbin and Strauss's [29] approach, within a pragmatic paradigm developed by Rorty.[30] Consistent with the tenet of pragmatic epistemology, that there are no fixed

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points from which reality can be observed, researchers and participants are understood as interactively constructing knowledge during the research process.[29 31] Resultant theory acknowledges "temporal, cultural and structural context" [31(p524)] and conditions that give rise to the phenomenon. The theory is understood as provisional, its value dependent on its relevance to real world problems and capacity to support change.

Study team

The study team comprises an early career researcher (Author 1) and three clinician-researchers with complementary expertise in the topic, recovery and methodology. The study is coordinated by Author 1 ('researcher'), a PhD candidate and registered psychologist with 14 years' experience working clinically within specialist youth mental health services. Authors 3 and 4 are experienced academics with backgrounds in clinical and educational/ developmental psychology. Author 2, also trained as a psychologist, is a health services researcher with substantial experience in qualitative research including grounded theory.

Study setting

This study is being conducted in Queensland, Australia with participants recruited from specialised Child and Youth Mental Health Services (CYMHS) funded by the Queensland Government. Delivered by medical, nursing and allied health professionals in multidisciplinary teams, CYMHS provide specialist assessment and treatment for young people (<18 years) experiencing substantial distress and disruption in daily functioning, typically meeting diagnostic criteria for severe or complex mental disorders. Consistent with national and state 'recovery-oriented' policy, CYMHS operate on the premise that young people can and do recover from mental disorders.[32]

Participants and recruitment

Participants are adolescents attending CYMHS in four study sites selected to represent geographic (regional/rural/inner-city), socio-economic and cultural variation. Eligibility criteria (table 1) are intentionally broad to promote recruitment of a sample with varied experiences.

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While sample size in GT is determined on the basis of credibility in context of the purpose of inquiry,[33] practicalities and time require an estimation. Based on team members' experiences and Cresswell's[28] recommendations for achievement of saturation, we aim to recruit 30 participants. Recruitment commenced July 2015 continuing through January 2017. At the time of writing, 19 participants have been recruited and data collection is continuing.

Table 1 Eligibility criteria for CYMH service users

Inclusion criteria

- aged 12 to 17 years, inclusive
- engaged with CYMHS for up to 3 months in current service episode
- with a diagnosable mental disorder representative of those typically treated at CYMHS
- Children's Global Assessment Scale (CGAS) score of 70 or less
- clinically assessed as having adequate psychiatric and cognitive capacity for study participation
- sufficiently conversant in the English language to complete interview

Exclusion criteria

- consumers with primary neurodevelopmental or organic diagnoses or impairments

Recruitment follows procedures outlined in figure 1.

Data collection

GT is a flexible methodology[29] that does not delimit the types of data acquired, techniques of collection or the way they are used. Indeed use of different kinds of data is recommended, providing alternate vantage points on the phenomenon.[24] In this study, primary data are participants' first person accounts, supplemented by two self-report quantitative measures of mental health. Data are collected in semi-structured interviews conducted at two time-points, first at recruitment then three to six months later, depending on participants' availability and engagement with CYMHS. Interviews are conducted by the researcher in private rooms at CYMHS, or other suitable facilities. The researcher uses a conversational approach following leads in participants' accounts, and participants' language to encourage articulation of experiences and views.

Data collection is supported by flexible use of a topic guide (table 2). The topic guide was informed by a review of literature related to young people's experiences of 'recovery',[23 34] interviewing young

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people,[35 36] interviewing for GT,[26 37] and the study team's clinical and research experiences with young people. Two visual aids, employed at the participant's discretion, are used to support description and critical reflection on experiences. First, early in both interviews, participants are invited to complete a timeline[38] of their 'journey' from awareness of difficulties to first interview, then from initial interview to the second. As timelines are constructed, participants are prompted to identify and explore personally significant events and feelings associated with these events. Second, a set of cards called 'ups and downs'[39] is available to support expression of feelings and description of experiences. Depicting a figure experiencing diverse emotions while floating at sea, the cards are used in conjunction with the timeline or separately.

The topic guide and use of timelines were piloted with two adolescents (known to study team members) who had experienced difficulties related to their mental health. When debriefed and invited to critique the interview, they reported finding the interview enjoyable and an opportunity to learn about themselves. No changes to the topic guide or interview process were recommended.

Table 2 Initial interview topic guide domains

Recognising and experiencing onset of mental disorders
- When, how, what difficulties came to awareness (commence timeline)
- Understandings of causes, meanings attributed
- How the problems impacted them at home, school, community, relationships and vice-versa

Initial actions, disclosures or noticing
- Others' noticing - when, how, their actions/ responses and what this meant to participant
- Participant's actions, disclosures – how, when, responses by others, what this meant
- What happened next? (continue timeline)

Timing/ Decisions regarding accessing support
- When, how, by whom decisions were made about getting professional help
- What led to the decisions being made, and what other alternatives were considered
- Initial feelings about these decisions - concerns, expectations associated with seeking support

Engagement with services
- Experience of accessing / engaging with services, where, when, why those
- Experience of initial processes – helpful/ unhelpful processes or experiences
- Suggestions for improvement

Expectations
- Expectations and hopes regarding the difficulties, what might help
- Perception of others' expectations, personal reactions/responses to these
- Expectations of the future

Change
- Perceived changes to date (if any) - how, when, under what conditions, in what contexts (home, school, neighbourhood, relationships)
- Perceived cause of changes (if any)
- Personal actions contributing to changes (if any)
- Effect of changes on self and relationships across home, school, neighbourhood settings

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Other Pertinent Issues
- Invitation to add other important ideas, experiences

To supplement personal accounts of change in mental health (if any), at each interview participants are also invited to complete two self-report measures: the Strengths & Difficulties Questionnaire (SDQ),[40] and Brief Multidimensional Students' Life Satisfaction Scale (BMSLSS).[41] The SDQ, selected because it is routinely used within CYMHS, measures psychological, behavioural and social difficulties, pro-social function and impact. Completion involves rating the extent to which 25 attributes are 'true' for the participant on a three-point scale ('not', 'somewhat' or 'certainly'). Designed for 4–16 year olds but validated for use to age 19, the SDQ has a reported Cronbach's alpha of 0.82 for a score of total difficulties, demonstrating satisfactory internal reliability. With consent, participants' SDQ scores collected by clinicians at treatment commencement are obtained from CYMHS to measure changes from treatment commencement to time-point one. Selected because it is commonly used within services to evaluate change to quality of life, the BMSLSS[41] generates a single 'satisfaction' score on a continuous scale of 1 to 5 within each of five dimensions (family, friendship, school/work, self, and living environment). Scores are summed to calculate overall life satisfaction. The BMSLSS demonstrates satisfactory psychometric qualities with Cronbach's $\alpha = 0.76$ to 0.85 in normative samples[42] and $\alpha = 0.77$ for an 11-17 year old clinical sample[43].

Audio recorded with permission, interviews last around 90 minutes. Following each interview participants are offered a $25 gift voucher to acknowledge their contribution.

Data management and analysis

Dependent on type, data are managed and analysed using SPSS Version 22 or NViVo10.

Following each interview, quantitative data are entered into SPSS.[44] Scores are calculated according to instrument guidelines. Within-case scores between treatment commencement and each interview time-point are compared to identify clinical and reliable change. Results are described (e.g. 'no change in social function', 'change- abnormal to normative range in emotional symptoms') then

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appended as a notated piece of data to the participant's interview transcript relating to the relevant time-point.

Interviews are transcribed verbatim. Along with timelines and notations about which picture cards are used, transcripts are uploaded to NViVo10[45] for storage and management. Prior to formal coding, each transcript is carefully read to identify chronology of events and important aspects related to them. A chronological summary of each case is made to track each participant's journey during the analytic process.

Combined data are then coded and analysed. As described by Corbin and Strauss,[29] analysis involves deconstructing, conceptualising and creatively reconstructing data in new ways, enabling development of new theories. Analysis in this study involves six iterative stages: (1) Within case analyses at time-point one; (2) Cross case comparisons at time-point one; (3) Within case analyses at time-point two; (4) Cross case comparisons at time-point two; (5) Within case analyses across time-points incorporating chronology; (6) Cross case comparisons across time-points. Analysis at each stage involves systematic coding and constant comparative methods. Each transcript is segmented into units of meaning which are labelled descriptively. Concepts thus formed are examined in relation to each other, with similar concepts categorised according to more abstract themes and labelled to reflect their similarity. Subsequent interviews are coded using existing and newly generated codes as applicable. Comparisons between concepts and categories are made within and between cases, codes either added to existing categories or new categories developed. As interviews progress, dimensions and properties of each category are established to form distinct, richly described 'saturated' categories. Theory building then commences, moving from inductive interpretation of data to reasoned analysis of how the categories relate.

Theory development

Strauss and Corbin's storyline approach is being used to construct and convey "a descriptive narrative about the central phenomenon".[46(p116)] The first step in theory building involves linking progressively developing categories chronologically and conceptually to form a storyline. Supporting theory formation, propositional statements are made regarding how categories relate, within which

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contexts, under what conditions and with what results (in context C, process A occurs resulting in experience B). Saturated categories are further examined to develop an understanding of the most salient issues and to identify a 'core' category or central storyline to which all other categories relate. Finally, the theory is situated contextually and boundaries established. Theory development is regarded as complete when the conceptual framework forms a systematic theory that reasonably represents, in a manner appropriate to use, the phenomenon of interest.

Rigour in analysis

Because qualitative research is inherently subjective,[47] the researchers' wise judgement and diligence are central to the integrity of the product.[48] Credibility relies on presentation of analysis such that readers are persuaded of "the plausibility of interpretations".[49(p204)] Rigour in GT involves ensuring adequacy and trustworthiness of the theory. In this study, rigour will be promoted in three interlinked ways: audit trail, critical dialogue amongst authors, and checking understanding with participants as the theory develops. First, to enable others to follow the process of analysis, procedural and analytical decisions are documented, including theoretical sampling decisions and progression, challenges to and resolution of hypothetical formulations.[50] Second, the analytical process is supported by dialogue between co-researchers who meet monthly during data collection and analysis phases of the research. Co-researchers act as critical friends, challenging the researcher to justify coding and analysis with reference to data, and test alternative explanations.[50] Corbin & Strauss [51] suggest 'opening up' analyses for peer scrutiny helps guard against bias by promoting reflexivity. Third, to ensure the theory remains grounded in data, the topic guide is refined to support exploration of developing categories, and tentative understanding of processes are checked with participants. Disconfirming data and exceptions are sought. Finally, 'reflexivity', self-awareness and metacognition regarding the researcher's influence on the research process and its outcomes,[52] are promoted by keeping a record of the researcher's thoughts, reactions and feelings during data collection and analysis. This self-reflection assists in identifying assumptions and biases, and provides opportunities to revise research questions and maintain openness to other possible interpretations of the data.

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Quality of the theory

There is consensus amongst proponents of GT that quality of the theory is first and foremost dependent on it being grounded in the data.[24 26 37] Dependent on approach and purpose, various other properties have been recommended as characterising a good theory. In this study, quality of the theory will be assessed on the basis of its fit, relevance, workability and usefulness.[24 26] 'Fit' is evidenced when categories and concepts relate to the data. Assessment of fit will be enabled by presenting data excerpts to illustrate concepts. Relevance relates to resonance of the theory[26]– the extent to which it 'rings true' to participants or others sharing their circumstances, eliciting an emotional response.[53] A workable theory explains and interprets what is happening in the process under investigation, accounting for any variation.[24] To enable assessment of workability, the storyline will be presented in diagrammatic and narrative form. Explanation of the storyline will include description of contexts and conditions within which events, actions or interactions occur. It will also describe the manner in which they vary, under which circumstances, and with what consequences. Pragmatically, the 'usefulness' of the theory should be assessed in relation to its applicability, its suitability as a basis for making recommendations within every day settings, and for generating discussion and further research.[26] Assessment of the theory's usefulness will be aided by outlining study limitations and recommendations for future research. Recommendations for policy and practice will also be made.

ETHICS & DISSEMINATION

Ethical considerations associated with this research

Researchers are obliged to balance participants' rights against risks in research participation. Children and adolescents have the right to express their views on matters of relevance to them.[54] One way of doing this is through research participation. To promote their right to consider participation in this study, (1) young people have direct access to age-appropriate research information via displays in service reception areas, (2) the researcher engages proactively with clinicians to identify potential participants, and (3) clinicians are encouraged to consider rights to research participation, thus not making decisions for the young person, for example regarding their interest in the study.

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Established protocols describe means of minimising risks in research participation for children and people experiencing mental disorders[55]. To maintain rights to privacy, potential participants are first approached by clinicians involved with their care. While clinicians are encouraged to invite all eligible service-users to consider meeting the researcher, to minimise risk, clinicians consider possible impacts of research involvement and assess potential participants' emotional capacity for participation before formally referring. Upon referral, research purposes and procedures are explained in age-appropriate language. The voluntary nature of the study and participants' right to withdraw without consequence are emphasised. Confidentiality and its limitations are discussed with particular focus on duty of care and management of privacy- secure storage of information, and participants' anonymity in presentation of results. Before inviting participation, potential participants are asked to describe in their own words what they are being asked to do and for what purpose. Participants provide consent in their own right, and co-consent is sought from parents/carers or another responsible adult familiar with the young person. During data collection, various strategies are employed to minimise power differentials. The researcher maintains focus on participants as experts in themselves and uses developmentally appropriate techniques during interviews, including use of participants' expressions relating to their experiences. Participants may, at their discretion, invite a support person to accompany them during interview, on the understanding that the researcher will not ask questions of the support person.

It is possible that participants experience emotional discomfort whilst sharing personal stories. Should participants appear distressed, they are encouraged to take breaks or terminate the interview. If participants disclose risk of harm to self or others, duty of care in the best interest of the young person takes precedence in line with the relevant professional code of ethics,[56] and issues of risk are referred, in consultation with the young person, to their clinician or carer. Participants expressing concerns about their mental wellbeing are referred to their treating team. A document detailing local, on-line and telephone mental health support options is also provided.

Dissemination of results

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The research will be reported as a PhD thesis and in various other formats, disseminated online through the University library, via workshops, conference presentations and published articles, summary reports to participating research sites, and within clinical peer/student supervision forums. Participants will be offered a summary of research findings or links to publications. Research and Consumer/Carer Advocacy groups within participating districts will be offered a copy of relevant publications.

When reporting study processes and findings, the 32-item consolidated criteria for reporting qualitative research (COREQ)[57] checklist will be used to address three domains relating to research team and reflexivity, study design, and data analysis and reporting.

DISCUSSION

To our knowledge, this is the first study using sequential interviews and grounded theory methodology to deliver a theoretical explanation of adolescent recovery. The theory developed in this study will be based on the select experiences of a particular sample, within a particular socio-political context, and it is acknowledged that others may have differing experiences. However, this is balanced by acknowledgement that the theory is partial and grounded in data documenting adolescents' perspectives regarding recovery and care needs. The theory will contribute to a much needed conversation, and in line with a pragmatic foundation, could inform recommendations for health, educational and research organisations regarding (1) planning and delivery of care for adolescents in ways that are right for them, (2) development of age-appropriate recovery measures, and (3) future research with adolescents experiencing mental disorders. The authors aim to improve care providers' capacity of to recognise and respond to young people's needs in a timely and effective manner.

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clinical staff for their involvement in recruitment to date are acknowledged. The contributions to research by the young people who have participated in the study to date are greatly appreciated.

Contributors All authors were responsible for the development and refinement of the protocol. LP wrote the draft and final manuscripts. SP provided substantial intellectual input into informing methodology and provided overall review of structure. GB and AO contributed to critical review, editing and final approval of the version to be published.

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Competing interests None

Ethics approval This study has been reviewed and approved by the National Health and Medical Research Council authorised Human Research Ethics Committees of Mater Health Services (Ref. HREC/14/MHS/208) and Griffith University Research (Ref PSY/26/15/HREC). Governance approvals have been obtained from each site.

Figure Legend

Figure 1: Recruitment Process

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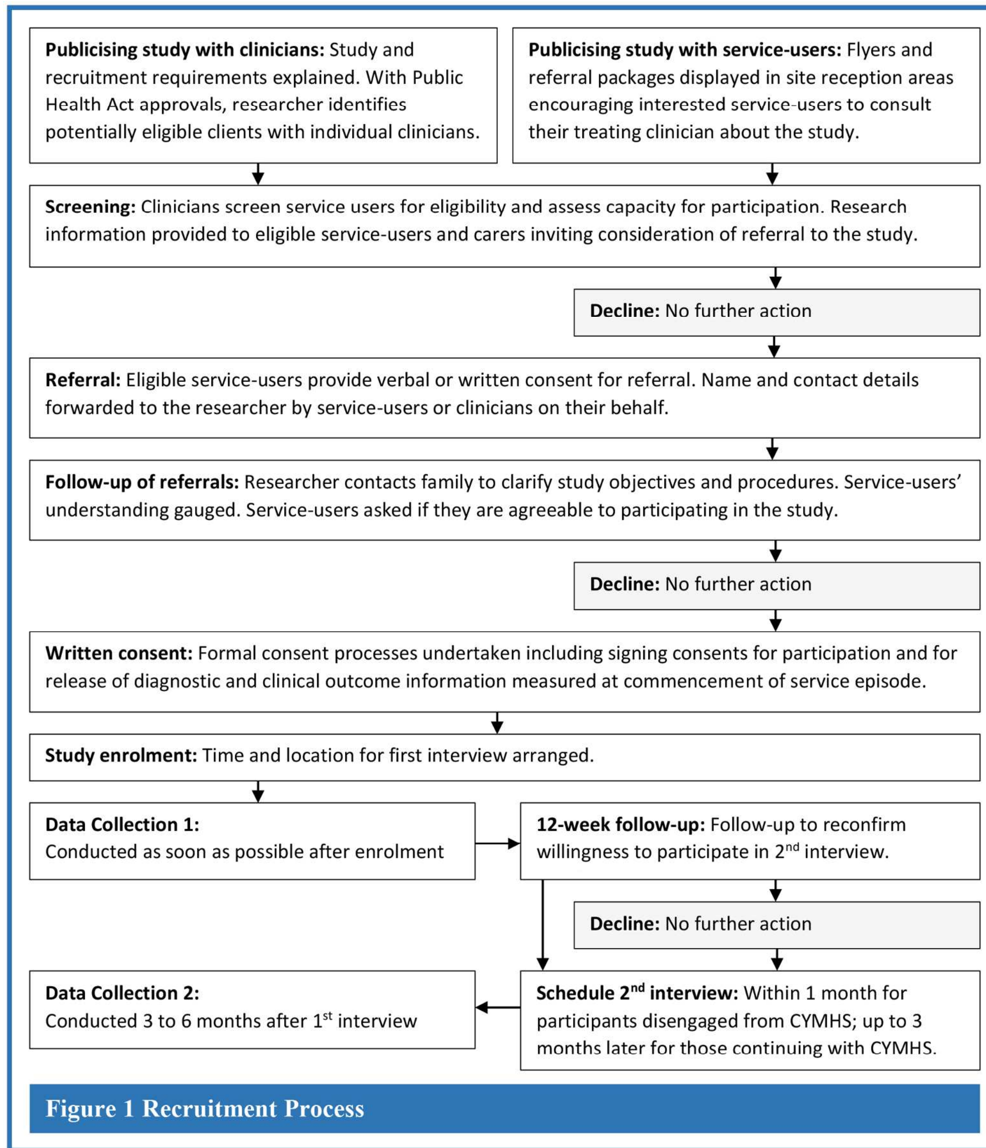

Figure 1 Recruitment Process

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