Ulster University

Exploring young adult service users' perspectives on mental health recovery

Short Report

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Contents **Page**

Acknowledgements 3

Research Team 4

Background 5

Aim 6

Sample 6

Methods 7

Phase one 7

Phase two 7

Phase three 7

Data analysis 8

Findings 9

Recommendations 11

Policy makers 11

Educators of healthcare professionals 11

Service providers 12

Young adults in the general population 12

Conclusion 14

References 16

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Background

Recovery remains one of the most widely debated aspects of mental health. Two main conceptualisations of recovery have emerged in the empirical literature. It has been suggested that 'Recovery from' symptoms involved the complete remission of symptoms, enabling the reinstatement of a contribution to society (Davidson and Roe 2007; Slade 2010). However, an alternative approach has emerged which views symptom reduction as only part of a more extensive journey to wellness. 'Recovery in' the experience of mental illness promotes a more holistic perspective which advocates that fulfilling and contributing lives can be lived despite symptoms. This occurs through the re-establishment of identity, social inclusion and self-determination (Anthony 1993; Davidson and Roe 2007).

Recovery in mental illness has been described as a non-linear process (Deegan 1988); a gradual individual journey involving a range of experiences (Kelly and Gamble 2005) but fundamentally a personal process (Davidson and Roe 2007; Wood *et al.* 2010). A consensus on the definition of recovery has yet to be achieved (Davidson *et al*. 2005a). However, Anthony (1993) proposed that the process of recovery can occur despite the presence of symptoms attributed to the illness. Leamy *et al.* (2011) identified its conceptual components; as connectedness, hope, identity, meaning in life and empowerment. While these are core elements there are often barriers to their sustainability requiring a dynamic interaction with internal and external process for real life application (Deegan 1993; Coleman 1999; Jacobsen and Greenley 2001; Onken *et al*.2007; Pitt *et al*. 2007; Kogstad *et al.* 2011).

Within their emerging adult role, Patel *et al.* (2007) suggested, young people will be embarking on employment, the development of a career, forming intimate relationships and living independently. It was Deegan's (1993) view that how an individual experienced themselves is inextricably linked to how they experienced their ill health, which would ultimately affect their experience of recovery. This resonates with Romano *et al.'s* (2010) suggestion that young adults experiencing the first episodes of schizophrenia do not feel they need to reconstruct self but to reshape it. This indicates that the challenges for recovery for young adults may be different from other age groups, thus providing the justification for this study.

Aim

The aim of this research study aims to explore young adult service users' aged between 18-35 perspectives on mental health recovery in Northern Ireland.

Study objectives were to:

- explore factors that feature in an individual's perspective of recovery;
- explore the 'temporality of being' within young adults' conceptualisation of recovery;
- investigate meaning and growth in suffering.

Sample

The latest population estimates in Northern Ireland (2014) suggested that there are 583,438 individuals aged between 16-39 years, representing 31.7% of the total population (NISRA 2011). Bunting *et al.* (2012) presented an epidemiological estimate of lifetime prevalence of mental health disorders in Northern Ireland. Results identified that young adults, defined as 18-34 years old, had the highest risk in all disorder classifications and as the age group requiring further research.

The voluntary sector provides vital support and service provision for young adults experiencing mental health difficulties, particularly in the fraught transition of child to adult mental health services (SCIE 2011). Therefore, the sample for this study was young adults, defined as within the age group of 18-35 years, and was recruited from the voluntary sector in Northern Ireland. Thus the exploration of young adult service users' concept of recovery could:

"hear their experiences and aspirations and translate these experiences into service design, planning, commissioning and delivery" (SCIE 2007, p.21).

Methods

This this study was devised using a three phased design beginning with phase one involving a concept analysis of the term recovery. Phase two involved the development of a collaborative phase with service user organisations to design an interview schedule used in third phase of the study to conduct 25 semi- structured interviews with young adult service users which was then compared to Phase one findings.

Phase 1: Concept Analysis

Despite the propagation of the term recovery, it remains an ambiguous concept with little consensus on its definition (Davidson *et al.* 2005a). A concept analysis of recovery was conducted to refine the meaning and the defining attributes of the concept. Rodgers' (2000) evolutionary method of analysis was used for this concept analysis, as it enabled an inductive exploration of the concept's evolution over time. The analysis involved an extensive literature review and also included other relevant sources, such as contemporary cultural influences. It was Rodgers' (1989, 2000) view that concepts do not develop in a linear way; therefore, this method is appropriate for the non-linear progression of recovery (Deegan 1988).

Phase 2: Engagement Group

In Northern Ireland, the HSC R&D Division strategy (2010) stressed that researchers should engage with service users and advocacy groups at the earliest stages of the research process. Service user involvement in research has become increasingly recognised in the exploration of personal recovery (Pitt *et al.* 2007) to ensure that service users "*own the definition"* (Weinstein 2010 p.31). Two engagement groups were developed within this study, enabling a collaborative process where service user's perspectives could inform the design of a semi-structured interview schedule.

Phase Three: Semi- Structured Interviews

To understand young adult service user understanding of recovery in mental illness required an in-depth and open interview process (Rubin and Rubin 2005). Therefore, face to face semi structured qualitative interviews with 25 services users was chosen

to facilitate a rich understanding of phenomenon or until data saturation had been reached (Parahoo 2006). Purposive sampling was used to select individuals from service user organisations whose experience will enable the exploration of this concept (Parahoo 2006). All interviews were recorded using a digital audio recorder, while the researcher noted all non-verbal responses or reflections in situ. Following the completion of each interview the recordings were immediately transcribed in totality by the researcher.

Data Analysis

Fleming *et al.* (2003) method for conducting a Gadamerian approach to data analysis has been employed in this study involving a cycle of four key steps which can be conducted to ensure understanding is achieved. Each transcript was read several times while listening to the audio to ensure that text was understood within context (Gadamer 1996). Each text was analysed again and colour coded in relation to theme. A separate word document was created for each theme; each text was again analysed and relevant items transferred to the corresponding documents (Turner 2003).

The four criteria for assuring the trustworthiness of qualitative research: credibility, dependability, transferability and confirmability were followed in this study (Lincoln and Guba 1985). Frequent peer debriefing sessions with the researcher's supervision team, in which transcripts were independently read and member checks with service user advocates following the phase 2 engagement process, have also ensured the credibility of this research design.

Findings

Six key themes emerged from the interviews. Subthemes are reflected in italics.

1. First Phases of Recovery

This was usually proceeded by weeks, months even years of extreme emotional distress, contained within the pretence of who they thought they should be. This led to an internal implosion where they taken right '***down to your foundations'*.** Within the context of an internal implosion participants described reaching a crisis moment where initial steps had to be walked in unknown personal territory by taking '***a step in the dark'***.

2. Services - A Losing Battle Straight Away

Access too, and engagements, with health care services were identified as direct barrier to recovery in two key ways - communicating ***distress*** - how that distress was communicated, how it was understood when it was communicated and what access this enabled them to have, or made them eligible for. Those few that gained access to help felt left on waiting lists for months, with limited hours of support but not the crisis points of night time and weekends. They were with meet service providers delivering their understanding of a ***Recovery Orientation*** which was not reflective of their current experience. Unable to meet the expectations of what recovery was portrayed to be, participants perceived it to be another assessment they had failed, another thing in their life they could not do.

3. Surviving Out of the Ashes

The experience of mental health recovery for these young adults involved channelling pain into personal power. Participants described that when down to their foundations they were faced with a critical decision to live from the pain or die from the pain. This process was underpinned by discovering an internal determination to survive fuelled by a sub theme - ***A Reason to Recover.*** This '***Reason to Recover'*** had to come from within themselves. Through analysis it became clear that they longed for emancipation from their circumstances. They longed for a peaceful life - as one participant put it "their back had been up against the wall long enough".

4. Let Go of the Pain not the Experience

Participants began to realise that pain could not be avoided but it did not have to be relived. They could use what they now knew about themselves and their lives to move forward. The importance of learning from their experiences required the transformation of an all-consuming pain into an internal, kinetic energy to progress the recovery journey. This process identified two subthemes '***Focus'*** and ***'Time'.*** This required refocusing their perception of themselves, their experiences and their lives had. This was not suddenly illuminated, but the narrow lens they viewed their life from got wider until they held a different perspective. However, the process was slow and arduous, they needed to give themselves time. They also understood that they could no longer live in the past and life had to be lived in the present, step by step away from the dark.

5. Recovery - Needs to be More than a Word

Participants described the confusion surrounding the word recovery, as when used at an inappropriate stage, it implied they needed to be fixed, like a hard drive or a broken vehicle. It did not express the experience. The ambiguity of the term recovery required the ***Application*** of personal influences or contextualising recovery within an individual's life to make it a relevant strategy for taking ***Control Over Life***
This became a developmental process, by applying the things that brought meaning to their life to their recovery process, meaning in life and meaning in recovery became inextricably linked. Real-life application made it a strategy that they could own and maintain.

6. Others are the "How"

Participants described experiencing numerous losses at this time. Loss of the social group, loss of social skills, missed milestones and broken dreams. Increased connection to others, through peer support, provided valuable learning to repair the social skill damage caused by illness. They began to see that their experience what they had lived and what they had survived, when shared, had real value and could create a connection with others through a knowing from the experience of emotional pain. Within this context recovery was understood as an increased ***connection to others*** through deeper connection to self.

Recommendations

Recommendations arising from the study findings are arranged into the priority groups with which they specifically relate:

Priority Groups

It is recommended that specific groups are targeted with information on young adult service user perspectives on mental health recovery as follows:

- *Policy makers*
- *Educators of healthcare professionals*
- *Service providers*
- *Young adults in the general population*

Policy makers

1. The definition of mental health recovery proposed in this study be incorporated into the mental health policy.
2. Specific mental health recovery focused policy and strategies should be informed by young adult service user's experience of the process as identified in this study, to ensure relevance of care provision.
3. Young adult service user perspectives be discussed at Government level to ensure policy makers understand the care provision issues.
4. The considerable risks to young adult's lives of a generic and service orientated understanding of mental health recovery, and the implications to their life perspective, should be made explicitly clear to policy makers.

Educators of healthcare professionals

5. Mental health educators should develop modules on mental health recovering, informed by service user perspectives. This should be embedded into the undergraduate curriculum of all education providers.
6. Educators of health professionals should incorporate the theory of "*The Suffering Human Being*" (Eriksson 2006) within a person-centred approach (McCormick and McCance 2006) to mental health care.

7. The communication barriers identified in these findings should inform the development of age-appropriate consultation skills training in pre- and post-registration professional development.
8. Educators should make it explicitly clear to health professionals that inadequate or insensitive healthcare communication is a significant barrier to mental health recovery.

Service providers

9. All service providers should develop service provision strategies informed by this evidence-based understanding of mental health recovery in young adults.
10. Such strategies should recognise and prioritise the pain and suffering that young adults are experiencing, specifically, at points of emotional crisis. Strategy development should be collaboratively prepared through engagement with service user groups, youth based organisations and local community groups, to ensure local strategic relevance.
11. Consideration should be given by Mental Health Care Providers to incorporate this understanding into the development of local crisis houses that provide accessible, confidential and “out of hours” support, offering recognition and compassionate care for young adults experiencing emotional crisis.
12. The risks posed to young adults by the lack of accessible and applicable services should be made explicitly clear to healthcare professionals.
13. The development of a directory of instant access, age-appropriate support and advocacy services should be developed by Health Service Providers. This should be distributed to all health centres, GP surgeries, pharmacies, schools, youth clubs, sports clubs and public services.
14. Strategies are developed within primary care services to enable young adults to feel supported and informed prior to attending appointments with their GP or the Community Psychiatric Nurse, through engagement with peer advocacy services.

Young adults in the general population

15. A Government strategy should be devised to raise the general populations understanding of the process of mental health recovery in young adulthood.

16. Mental health recovery information and support should be widely available to the general population. This should be communicated through meaningful and relevant mental health promotion strategies developed through collaboration with the Public Health Agency and service user organisations.
17. Consideration should be given to the development of age-specific mental health promotion strategies, informed by young adult service users' experience of mental health recovery.
18. The development of considered and contemporary anti-stigma campaigns, which promote mental health recovering, are vital. Public health agencies, the arts community and youth focused organisations should collaborate with service users to design a culturally relevant anti-stigma campaign targeted at young adults in the general population.

Conclusions

This research study has contributed to knowledge and research within the field of mental health recovery research. Phase one findings have proposed a new conceptual definition of mental health recovery proposing that the term “recovery” is not reflective of the identified conceptual characteristics (McCauley *et al.* 2015). Phase two has developed a novel and innovative method to collaborate with service users in the co-production of a relevant semi-structured interview schedule, contributing to the ever growing role of service user co-production within mental health research.

Findings from phase three have, for the first time, presented the views of young adult services users in Northern Ireland on mental health recovery. Additionally it has enabled a novel comparative analysis of between the conceptual characteristics of recovery and how the concept is understood by young adult service users. It has revealed recovery is understood as an uncharted timely personal process of engaging and transcending pain, requiring their perceptions of painful experiences to be refocused to own the experiential learning while discarding its destructive potential.

The findings from this study have suggested that young adults must engage with their pain in a supported and confirmed way, applying the influences that bring meaning and depth to their life and to the process. In so doing, they not only engage their pain but get to know it, understand it and use it as a power source, enabling meaning in life and meaning in mental health recovery to become inextricably linked. The findings highlight that the transformative potential of this process is significant and enables an emotional development, social re-engagement and connection. If recovery is descriptive of any aspect of the process, it is the recovery of an active and purposeful life force. However, recovering necessitates a re-imagining of self, of others and of life, which involved re-formulating the re-emerging self.

The novel comparative analysis of the findings from phases 1 and 3 reveal that conceptual modification of recovery was required. The findings suggest that

modification would ensure the relevance, applicability and ownership of mental health recovering in young adulthood. They further reveal that recovery involves the dynamic movement of the individual between phases in the process of recovering. Therefore, its definitive outcome based derivation and contextual associations are misleading and undermining to the internal process an individual embarks on. The findings suggested that the quest for a word for the process has been, in itself, unfocused and problematic, as the conceptual context has evolved (Rodgers 2000) and dissonance between clinical classifications and subjective experience exists.

In conclusion, the disruption of ill health on the developmental stage of young adulthood, where careers, relationships and an individualised identity is being formed (Patel *et al.* 2007) could significantly be impacted by presenting the process in age appropriate terms as a strategy for "*recovering"* (Participant Quote P8). The findings propose that Eriksson's (2006) "*drama of suffering"* is reflective of the internal process of mental health recovery in young adulthood. Weinstein (2010, p.10) argued that service users must *"own the definition"* of recovery; therefore, using an explanatory model of "*use that stuff you wanna bury*" can transform an illness narrative (Kleinman 1988) to a wellness strategy for *"building a better life"* (Participant Quote 24).

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