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Recovery from Schizophrenia: Developing context utilising the literature

The word recovery has been utilised, both in and out of context, for some time within the field of mental health. This review of the literature aims to enlighten and assist in the contextualisation and understanding of recovery and the relationship it has for people with a diagnosis of schizophrenia. We have evolved to a position where people with a diagnosis of schizophrenia are 'expected' to demonstrate some form of recovery (Frese *et al* 2009). This offers such a contrast from the notion of inevitable decline which had been postulated by Kraepelin and many others of the time. Deegan (2005, p1) asserts that, "Despite the enduring legacy of pessimism ... a majority do recover". This is evidence that recovery from schizophrenia has evolved considerably since its recognition as a psychiatric condition (Frese *et al* 2009).

This paper contributes to the literature by offering a fresh approach which assists in maintaining a focus upon recovery by striving to achieve the following goals;

- * Providing clarity around the existing differences between service user and service provider views on recovery.
- * Demystifying the rhetoric regarding recovery by illuminating the personal and subjective nature of recovery, as opposed to purely symptom control.
- * Developing the importance of the story of the person, so that people are heard and appreciate how they can contribute to their own recovery.
- * Provide an opportunity for the reader to appraise the literature in order to facilitate a recovery approach in the best context.

Recovery, very much like schizophrenia, propagates debate regarding the lack of an agreed definition. Bonney & Stickley (2008) identify that generally, there is no clear consensus regarding recovery and it therefore remains very much contested. Many authors state that there is not yet a definitive definition of recovery (Onken *et al*, 2007; Kogstad *et al*, 2011). The most commonly cited definition was developed by Anthony (1993), who was one of the intellectual founders of the recovery movement (Shepherd *et al*, 2008).

"Recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills and roles. It is a way of living a satisfying, hopeful and contributing life, even with the limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness"
(Anthony, 1993, p15)

Recovery cannot be regarded as a new concept, when observing the consumer/survivor self-help movements and groups there is evidence of the concept of mental health recovery since the 1930s

(Onken *et al*, 2007). The idea of recovery in schizophrenia has been ‘cherished’ by a small group on the fringe of the field of mental health for over 20 years (Roe & Davidson, 2008) and has emerged at the forefront of the recent policy agenda (Bonney & Stickley, 2008). The advent of recovery was partly driven by dissatisfaction with the traditional medical model (Ahmed *et al*, 2012). It has been purported by Jacobsen and Curtis (2000) that traditional systems had indeed fostered disability, alienation and marginalisation. Longitudinal research studies had led to the concept of ‘recovery from schizophrenia’ with its emphasis being the eradication of clinical symptoms. In contrast the service user movement embraced the concept of ‘recovery in schizophrenia’ which allows service users to retain some degree of control over their lives despite the possible presence of symptoms (Gordon, 2013). It was recognised by Frese *et al* (2009) that the medical model, in conjunction with deinstitutionalisation, began to address the functioning of former patients and consequentially the notion of recovery from schizophrenia began evolving, initially under the guise of rehabilitation. It had long been stated that the recovery process was the foundation of rehabilitation services (Deegan 1988).

For service users like Pat Deegan it took time to overcome the feeling of being ‘dehumanized’ following her diagnosis of schizophrenia. “Dehumanization is an act of violence, and treating people as if they were illnesses is dehumanizing” (Deegan, 2002, p9). Pilgrim (2009) offers reassurance that deinstitutionalisation and the possibility of regaining citizenship for those previously dehumanised encourages optimism. Some previous ‘treatments’ of people within institutions was abhorrent with no consideration of potential for recovery. This was due to a ‘eugenic axiom of degeneracy’ which existed (Pilgrim, 2009). The eugenics movement of the late 19th and early 20th centuries supported genetic explanations for stigmatised characteristics like mental illness which were governed by policies and resulted in marriage restrictions, sterilisation and even extermination (Kelves, 1985).

Despite deinstitutionalisation and community care becoming common place in the twentieth century one does not imply or lead to the other (Pilgrim, 2009). This is reference to the fact that during ‘community care’ some people felt abandoned often slipping between the cracks in service configuration or being overlooked by this regime. Consequentially, Sayce (2000) highlights that in the public mind ‘community care’ was associated with failure. Allott *et al*, (2002) commented that in a UK context the majority of people within the mental health system are given little hope of recovery from their experiences and staff were lacking in knowledge with regards to recovery. The Chief Nursing Officer’s Review on Mental Health Nursing (Department of Health, 2006) states nurses should use recovery principles in every aspect of their practice. Although things are changing and we have a much clearer structure for community services in England, Boardman & Shepherd (2012) state that

improvement is still required in respect of the quality and content of these services. Despite this, it has been reported that; “An understanding of recovery as a personal and subjective experience has emerged within mental health systems” (Slade *et al*, 2014, p12).

The language of ‘recovery’ has become a common feature in mental health policy and practice in the UK and the agenda of recovery encompasses diverse perspectives from policy makers, service users and professionals (Spandler & Stickley, 2011). People who have experienced mental illness have been increasingly vocal in communicating what their experiences are with mental illness and also what assists in moving on beyond mental illness (Slade, 2010). These narratives and service user perspectives have assisted everyone in attempting to tailor interventions to facilitate an individual’s recovery. However, these opinions within the literature about recovery are wide-ranging and whilst they cannot be characterised uniformly they do provide valid indicators of what recovery looks and feels like from the inside (Slade, 2010). Spandler & Stickley (2011) add issues raised have addressed concerns around what it feels like and the seemingly lack of compassion in mental health services.

Lehman (2000, p329) advises caution and states, “Recovery has become a loaded word in the mental health field”. This may be due to recovery being a dichotomous proposition, as some people take recovery to represent hope that they may go on to pursue a fulfilling life. In contrast, others view ‘recovery’ as rhetoric for people who have been oppressed victims of the system; these feelings gave rise to a philosophy of anti-psychiatry and people wishing to be free of professional treatment. When attempting to clarify this ambiguity Schrank & Slade (2007) stated that the term recovery has two meanings which are: ‘Service-based recovery definitions’ and ‘User-based recovery definitions’. Service based recovery definitions rely on symptom remission and reduction in use of medication, whereas user based recovery definitions address personal growth and development in overcoming the experience of being a mental health patient.

The concept of recovery has been defined in countless ways and Silverstein & Bellack (2008) organised them roughly into two groups. The first group reflect recovery as an ‘outcome’ (descriptions that desire operationally defined criteria to be achieved) and as an on-going ‘process’ of identity change. Therefore it is easy to distinguish, again, the areas where service providers and service users may have a differing stance and similarities can be drawn against the work of Schrank & Slade (2007). However, this may have developed from Bellack (2006) who viewed recovery as an outcome developed from the search for clinically meaningful and psychometrically reliable outcome measures, whereas appreciating recovery as a process developed primarily from service users

attempting to raise the profile of their perspective within practice and research. Liberman & Kopelowicz *et al* (2005) argued there is difficulty in separating 'process' and 'outcome' due to the elements of these two perspectives 'reverberating' with each other. Gordon (2013) adds that despite service users often claiming to reject the idea of 'outcome', their descriptions generally embrace both process and outcome; and as examples Gordon cites Deegan (1988) and Anthony (1993). Atterbury (2014) notably points out that measuring outcomes is not 'unimportant' but individually outcomes do not afford the ethical justification for a recovery-orientated approach. Gordon (2013) had expressed disappointment that the many recovery-focused outcome measures available are not being adopted and applied by researchers, academics and the pharmaceutical industry. "This is especially perilous given that outcomes measures often drive the types of service provided" (Gordon, 2013, p271). This is viewed as 'perilous' by Gordon (2013) as recovery as an outcome implies people are condemned to hopeless unending journeys which may also encourage apathetic services which would continue to be determined by symptom-focused outcome measures. This may be viewed as regression to a maintenance approach for people with a diagnosis of schizophrenia.

Another similarly contested factor is whether recovery is an approach, a framework or a model with different authors putting their own interpretation on proceedings. Warner (2009) favours the term '*The recovery model*'. This may be derived from earlier opinion by Andresen *et al*, (2006, p972) who state that "... there is a need for a model and a method of measuring recovery as the concept is described by service users". Thornton & Lucas (2011) sketch some of the issues and articulate a possible recovery model for mental health. However, they state clearly that their aim is to "clarify the options rather than defend the model that emerges" (Thornton & Lucas, 2011, p24). Whilst many issues are raised and discussed from other perspectives within their paper it is difficult to ascertain the level of conviction that Thornton and Lucas (2011) have in the 'model'. A position statement by consultant psychiatrists in two merging London NHS trusts stated that, "Whilst some people refer to a 'Recovery Model', it is probably better to speak about Recovery ideas or concepts. A model would suggest that there is a manual somewhere" (South London & Maudsley NHS Foundation Trust and South West London and St George's Mental NHS Trust, 2010, p11). Kogstad *et al*, (2011) predict that the recovery approach needs to go beyond attempts to construct models for recovery-orientated practices and should therefore be a 'non-linear' process. Perkins & Slade (2012) identify recovery as a 'journey' but it was Unzicker (1989) who was one of the first to generate the idea of recovery being a journey. As a self-confessed 'survivor' of services Unzicker's drive and determinism was developed from the rejection of the medical model. Many view recovery, and the recovery movement in particular, as a challenge to the medical model (Deegan, 2002; and Frese *et al*,

2009). Mountain & Shah (2008, p241) worryingly identified that, "... many psychiatrists seem detached from this approach [recovery]. Sceptics suggest that it underplays the value of psychiatric treatment and services and offers false hope". In response to the recovery movement, Mountain & Shah (2008, p244) go on to state, "There has been a confusing range of responses among psychiatrists. Some have been bemused, dismissive or defensive". In spite of these comments Pilgrim & McCrainie (2013) state that, whether rhetorically or otherwise, the personal journey approach to recovery has found a strong presence for all stakeholders. The growing complexities associated with the notion of recovery were also addressed by Pilgrim & McCrainie (2013, p44);

"... we have seen recovery in a number of either/ors: an internal versus an external process, a process versus an outcome and a clinical goal versus a socio-political goal. One might be discussing recovery-as-experience, recovery-as-evidence, recovery-as-ideology, recovery-as-policy or recovery-as-politics"

Pilgrim & McCrainie (2013, p44)

In an attempt to progress and operationalise the literature around recovery Andresen *et al*, (2006) developed a 'stages of recovery' instrument. This was developed from a consumer-orientated definition of 'psychological recovery' from their earlier work in 2003 and this was described as; "... the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination" (Andresen *et al*, 2003, p588). The whole premise of recovery is based upon finding a new self and position as opposed to rediscovery of the former, premorbid, self (Deegan, 1988). Andresen *et al* (2003, p589) developed a 'Four component processes of recovery' (Finding hope, Redefining identity, Finding meaning in life, and Taking responsibility for recovery). At this period in time other studies had also identified stages or phases in the recovery process but with regard to the exact delineation there was no consensus. An earlier study from Davidson and Strauss (1992) addressed the sense of self in respect of recovery and whilst this study did not specifically address people with schizophrenia per se there were 25 participants from the total of 66 with this diagnosis. Davidson and Strauss (1992) developed 'four aspects' (Discovering the possibility of the self as an agent, Taking stock of strengths and limitations, Putting aspects of self into action, and Using the enhanced sense of self as a resource in recovery). The significance of personal change is not missed here as these aspects adhere, to some degree, to Kurt Lewin's (1951) three-step model of change management. Andresen *et al*, (2003) drew comparison between five studies prior to drawing up their own 5-stages of recovery. These five stages consisted of; Moratorium, Awareness, Preparation, Rebuilding, & Growth. These stages are not necessarily a linear progression that all go through, but are best viewed as aspects of engagement within the process of recovery (Shepherd *et al*, 2008). Components, aspects or stages of recovery highlighted and suggested by various authors have contributed to a drive towards an understanding of recovery, even though not always adding clarity in every case.

In 2005 Laurie Davidson identified that we cannot implement programmes of recovery taken from physical illnesses in the field of mental health. Davidson’s (2005) notion that ‘self-management models’ and ‘service user experiences’ have more value than models originating from physical health. Regarding definitions, Davidson was in support of and utilised the notion of recovery previously highlighted by Anthony (1993) whilst also utilising the work of Andresen *et al*, (2003) in developing clarity for the UK perspective. This was beginning to signify the direction for recovery in the UK as Davidson developed his work in the Devon Recovery Group to identify ‘The Principles of Recovery’ (Davidson, 2008). These principles have been replicated and advocated in many areas including Manchester, Cornwall and even Ohio, USA. Those mentioned also advocate the definition of recovery by Anthony (1993) and the ‘four component processes of recovery’ (Andresen *et al*, 2003).

We are reminded by Deegan (2002) that recovery is not the privilege of an exceptional few clients, but as empirical data indicates most do recover. Atterbury (2014) asserts that if the promise of recovery and recovery relationships are withdrawn from service users it is an injustice and a moral violation. To transfer recovery focused-approaches into practice it is useful to comprehend the regular themes arising from people who have recovered. Table 1 compares three studies illustrating the themes of people who have recovered. The study by Schrank & Slade (2007) identifies components of the recovery process as defined by service users, whereas the other studies are themes derived from the literature.

Table 1. Comparison of Recovery Themes

Kelly & Gamble (2005)	Schrank & Slade (2007)	Slade (2009)
Hope	Hope	Hope
Mentorship		
Spirituality	Spirituality	
Growth		
	Responsibility & Control	Personal Responsibility
	Empowerment	
	Connection	
	Purpose	
Being an Individual	Self-Identity	Self-Identity
	Symptom management	
	Stigma	
		Meaning

The concept of hope remains a central tenet of recovery and is reported widely in the literature (Hobbs & Baker, 2012). The 'twin challenge' of addressing the impact of the mental health problem on a person's life and also fostering a positive future vision, for the mental health worker is appreciated by Repper & Perkins (2003). Following consultation with 'consumers' Jacobson & Greenley (2001) had previously introduced the concept of *internal* and *external* conditions in recovery. The internal conditions referred to; hope, healing, empowerment and connection. The external conditions defining recovery are; human rights, a positive culture of healing and recovery-orientated services.

Langeland *et al*, (2007, p276) identifies three important healing factors within the recovery process. These factors are that participants i) perceive themselves as something other than just a diagnosis or a disease, ii) explore themselves with respect to their whole person, and iii) take control of their own lives. An appreciation of a salutogenic approach by mental health workers would be favourable to support this. The basis of improving all aspects of life simultaneously through holistic healing was proposed by Antonovsky (1985). In agreement Atterbury (2014, p184) states; "A more holistic view of mental health offers recovery as the hopeful protagonist in a narrative of health not illness". This basis of salutogenesis is opposed to the traditional perspective of health, regarded as pathogenic, with its emphasis more on disease and biological mechanism. Salutogenesis proposes that the diagnosis becomes secondary to the story of the person, with the person understood as an active system that interacts with the environment utilising both internal and external conditions (Langeland *et al*, 2007), very much in alignment to those described by Jacobson & Greenley (2001). The presence and ability to utilise salutogenesis was illustrated in a study by Ventegodt *et al*, (2008), addressing clinical holistic medicine in the recovery of working ability. Ventegodt *et al*, (2008, p221) concluded; "The patients are motivated for human development and engage in existential therapy in spite of this being highly emotionally painful at times where old trauma are confronted and integrated". This may resonate for people with a diagnosis of schizophrenia, as a potential for approaching recovery.

Overall, the concept of salutogenesis may have informed many other approaches to recovery, including most of the themes identified in Table 1. The benefit of a salutogenic approach is increased when service users are prepared to assume responsibility for their own life (Ventegodt *et al*, 2007). This has been appreciated for some time as Liberman & Kopelowicz (2005) postulate, due to the fact that schizophrenia is often associated with dependence on others, recovery should include a dimension associated to independent functioning. This has a big impact upon mental health services and approaches, as Copeland & Mead (2000), who use their own experiences to suggest that mental

health workers have to 'be human' and regard recovery orientated relationships as real and authentic despite changes in roles. Repper & Perkins (2003) emphasise that the central issue in effective relationship formation is the ability to value people as equals. Silverstein & Bellack (2008) add that terms, such as hope, empowerment and self-determination are often employed in a vague manner. Kogstad *et al*, (2011) had discovered that recovery factors experienced by service users are not always compatible with professional approaches. Beck *et al*, (2012, p564) offers one explanation, "People appear to hold an individual representation of what it means to be recovered". From personal experience Rufus May states that recovery from social expectations was a bigger challenge than the psychosis itself and as a consequence he sees that "Recovery lies in the social contexts within which this process occurs" (May, 2000, p10). Many subjective views of recovery occur, with one reason being due to personal understanding of recovery altering over time (Slade *et al*, 2014).

The individual and personal journey of recovery for service users necessitates services to alter the focus of care and treatment (Lloyd *et al*, 2008). Atterbury (2014) indicates that the difference between traditional mental health practices and recovery-orientated approaches is that if we are utilising a recovery focus then the locus of control should remain with the service user to the greatest extent possible. This will, hopefully, avoid the traditional paternalistic approach based on maintenance. Aston & Coffey (2012) warn that without understanding of the concept of recovery mental health staff will struggle to deliver a recovery-orientated service.

Yates *et al*, (2012) explored the social and environmental condition in which recovery occurs, concluding that recovery seems unlikely and can never meet the needs of the people if the environment is structured in a manner that damages, excludes and discriminates against them. Aston & Coffey (2012) also identified that nurses demonstrated role uncertainty in relation to recovery and felt that, despite rhetoric to the contrary, the concept had been imposed upon their profession. In spite of this, some service users remain positive and Mayes (2011) states that whilst choice is important, the combination of self-help and mainstream services can offer the best approach. It had been identified by Slade (2010) that aspects of individuals engaging or re-engaging in their life are recurring features from the recovery narrative that allow people to discover meaning and purpose through valued identity and social roles. This is indicative of 'personal recovery' which involves working towards better health, regardless of the presence of symptoms as previously highlighted. One of the main indicators of personal recovery, according to Giusti *et al*, (2014) is cognitive insight, which refers to the ability to evaluate and correct distorted beliefs and assumptions and the increase in ability to do this presents a positive correlation with personal recovery. This approach is indicative of wellbeing rather than the treatment of illness.

Whilst conceptualising and delivering recovery in the context of service provision Woods *et al* (2013) identify that there are a number of idiosyncratic perspectives which need to be taken into account. When Slade *et al* (2014, p14) addressed the ‘uses and abuses of recovery’ they identified seven misperceptions or abuses of recovery;

- 1) Recovery is the latest model
- 2) Recovery does not apply to ‘my’ patients
- 3) Service can make people recover through effective treatment
- 4) Compulsory detention and treatment aid recovery
- 5) A recovery orientation means closing services
- 6) Recovery is about making people independent and normal
- 7) Contributing to society happens only after a person is recovered

The emphasis by Slade *et al*, (2014) centres on the implementation of recovery-orientated practices and facilitating inclusion. This type of recovery will involve transformation within, and impact upon mental health services and will not be easy to transform as it impacts upon human systems. Recovery-orientated practices are viewed as ethical by Atterbury (2014) as they recognise and respect every person’s personhood and dignity. Extending beyond a reductionist view of symptomatology recovery orientated services help individuals reconstruct their lives in a meaningful way (Mathur *et al*, 2014). The culture of care underpinning how service users are valued, understood, related to and position within the organisation should be central to the delivery of interventions and service systems (Papadopoulos *et al*, 2013).

ImROC (Implementing Recovery through Organisational Change) was established in 2008 by the Department of Health in England and is a joint initiative between the Centre for Mental Health and the Mental Health Network NHS Confederation (Shepherd *et al*, 2014). One of the main tenets of ImROC is;

“While the ideas of recovery and recovery-oriented practice have the potential to transform mental health services, we need to look beyond what is provided by these services and examine the whole range of resources and opportunities that can support quality of life, full citizenship and human rights for people with mental health problems.” (Boardman and Friedli, 2012).

Approaching recovery and utilising approaches as suggested by ImROC would also go some way to ensuring that services employed a more ‘practice-based evidence’, in doing this the voice of the service user would be privileged and given equivalent status with the more conventional models of presenting evidence as suggested by Ramon *et al*, (2009). However, caution must be exercised that the case made by Roe *et al*, (2007, p173) does not become true, when they state that; “If recovery can be taken to mean anything, then it comes to mean nothing at all”. A similar statement had been

made earlier by Lester & Gask (2006) when they commented upon how broadly the term recovery was being made that it bordered on becoming meaningless. However, despite advances since these comments there is a lot of work to be done to enable services to be more effective in enabling recovery for people with a diagnosis of schizophrenia.

The REFOCUS programme is a recent development, which is primarily aimed at promoting recovery in adult mental health services. The REFOCUS manual now in its second edition addresses the implementation of pro-recovery interventions by staff and these interventions impact in two ways; *Recovery promoting relationships*, and *Pro-recovery working practices* (Bird *et al*, 2014). A summary of findings from the REFOCUS programme was published by Fortune *et al* (2015) and this offers a clear demarcation between clinical recovery (emerging from mental health professionals) and personal recovery (emerging from people with lived experience). Importantly, there is clear reference made by Bird *et al* (2014, p8) that “... recovery can take place within, partly outside or wholly outside the mental health service”. This is a clear message that people should be encouraged to recover in a fitting environment, not just within mental health services.

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