Families and Recovery:
Beyond clinical and social inclusion perspectives

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Abstract: This paper explores the theoretical connections between principles of social inclusion and the recovery moment in mental health, identifying points of convergence and divergence. Social inclusion and recovery, while developing from different starting points, converge in recognizing the broader personal, family and community contexts, in which mental health problems emerge, and the impacts of those problems. A significant part of the context for recovery and measures to achieve social inclusion, remains the person's family. Current models of recovery probably overlook the distress of families in the recovery journey. The paper considers the extent to which families have a role both in supporting the recovery of a family member, and in making their own recovery journey. The paper further suggests the need for ongoing research to explore the way the family recovery journey changes over time.

Keywords: families; mental health; recovery; "social inclusion"; "recovery journey.

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Introduction

Over the last three decades, Peter Huxley and his team have challenged mental health and social services to embrace a broad view of the impact of serious mental illness. They have been able to capture the truth so evident to those of us who have worked as social workers in this area, that the social and economic costs of mental illness are often life-long and extreme. In Australia, the Living with Mental Illness studies (Morgan et al., 2014) confirmed the connection between psychotic illness and poverty, revealing the poor housing and employment options for many, the poor health, the poor access to basic services, and the profound loneliness that often accompanies the experience of serious mental illness. Peter's program of research was able to conceptualize this experience not simply as the enduring presence of unpleasant symptoms and treatments, but as a process of exclusion from the benefits of ordinary citizenship. His team set about trying to measure the concept of social inclusion as it applied to the consequences of mental illness. Many of the dimensions of social inclusion, such as housing, employment, education, health, economic factors, and access to services, can be measured as evidenced by the work of Morgan et al. in the Living with Psychosis studies (Morgan et al., 2014). The efforts of Peter and his team in developing standardized measures that have utility in the clinical social work space will no doubt be an enduring legacy of his work (Huxley et al., 2012).

At the same time, the recovery movement was challenging the reductionism and pessimism of clinical services that were focussed solely on managing symptoms. The social inclusion research and the recovery movement have worked together to change the discourse of mental illness in clinical and social services, policy and practice. It is beyond the scope of this paper to fully address the interface of recovery and social inclusion. Perhaps others will take up this challenge in this collection of papers. Our own work has been in the area of families and psychosis, the importance of the family in supporting recovery, and the impact of the illness on families. Families in this context are defined as those who care and are involved in a person's life, those that are involved in the intimate informal social network and include family, friends and other supporters. We will share some of our own ideas about the way that recovery theory might provide a framework for working with families of people with serious mental health problems. We will offer a very brief summary of the two movements, using literature reviews to identify similarities and differences of emphasis. Both social inclusion and recovery are useful, complimentary concepts in providing a theoretical framework for engaging with families.

Social Inclusion and Recovery

A review of social inclusion concepts by Cordier [Cordier et al., (2017)] described three general principles of social inclusion – connectedness, participation and citizenship. When applied to social work and the human services, there are five dimensions of inclusion- growth of relationships, choice and control, experiencing socially valued roles, sharing ordinary spaces and making a contribution. While conceptually useful, this framework defies that kind of measurement that Peter and his team worked hard to promote.

A rigorous literature review of social inclusion research by Filia and her colleagues (Filia et al., 2018) identified thirteen principles relevant to mental illness. They conclude:

> social inclusion is multifaceted and complex, comprising of a range of key contributors related primarily to participation in social activities, good social networks with support available, stable and suitable housing in a safe and well-resourced neighborhood and involvement in employment or education (current and/or acquired education) (Filia et al., p. 12).

Emerging from different theoretical and practical roots, Recovery as a philosophy developed partly from the rehabilitation movement (Anthony, 1993) but mainly from the consumer empowerment movement (Bland et al., 2021). There have been several studies that have sought to conceptualize the principles of recovery. Recovery in general has been defined as being able to live a meaningful life, finding hope, having a sense of purpose, connections and gaining an independent life. (Davidson et al., 2005; Slade, 2009; Leamy et al., 2011; Bland and Drake 2020). Limited studies have focussed on how recovery is relevant and experienced by families.

There are clear synergies between recovery and social inclusion concepts. Both are firmly rooted in the lived experience principles that demands a limit to the capacity of diagnoses to define identity. Both emphasize the importance of connection and understanding the family and broader social context of the individual. Social inclusion focusses on the economic welfare of the individual, and the need for a range of welfare services such as housing and employment support. Recovery recognizes that these are likely to be central to the desire of individuals with mental illness to live in basic comfort. Both agree that participation in the life of the community is essential to living a "contributing life."

Recovery, however, has generally been conceptualized as a more personally constructed goal (Slade, 2009) with individuals choosing personal goals to determine success. Despite efforts to promote standardized measures of recovery (for example, Recovery STAR [Recovery Star Outcomes Group]) many mental health workers and service users prefer to work together to set personal, rather

than standardized, outcomes. Recovery also emphasizes less tangible principles such as "sustaining hope" and "meaning making" in what is seen as a dynamic recovery journey. Recovery is a concept that is more easily owned by mental health service users, and has, perhaps, more immediate personal resonance than the more political concept of social inclusion. Thus then, while there are distinct synergies, there are differences of emphasis. At a policy level, social inclusion offers a more robust argument for seeing mental illness as a social justice issue. Recovery, perhaps, is a more comprehensive basis for engagement and work with individuals and the principles provide a way for people to work through the experiences.

While many families identify with the recovery framework and describe their experiences around the various parts of the model, there is now increasing suggestions that the recovery model is perhaps, too optimistic and positive about the family journey and that many families experience significant trauma, a deep sense of loss. and crises experienced that signalled the importance of setting the positive aspects of recovery against the distress they had endured – a deep sense of loss and grief, and the enduring effects of trauma (Wyder et al., 2021)

Recovery in a relational context

Personal Recovery is often defined as personal and unique to each person and focuses on living a satisfying, hopeful, and contributing life even with limitations caused by the illness (Anthony, 1993; Davidson et al., 2005). As a result, the focus has been almost exclusively on the individual and the "intra-personal" dimension of recovery rather than giving weight to the "inter-personal" and the importance of a person's relationships, particularly within families and social networks (Price-Robertson et al., 2017). Recovery however occurs within a relational context and a person's social network (Topor et al., 2006; Bland & Drake, 2019). The strong focus on individual journeys as well as self-determination, does not consider the relational nature of mental health distress and recovery and it fails to capture the complex and relational nature of human experiences (Price-Robertson et al., 2017; Wyder et al., 2021).

In other research and writing we have explored the various ways in which families have been positioned in the mental health literature. Most often families are described as either the burdened carer or simply as being supportive of a person's recovery (Bland and Foster, 2012; Wyder and Bland, 2014). While families are considered as central to a person's recovery, there is still limited understanding of the impact of an illness on the family and the family's experiences of recovery. We have considered the application of a recovery framework to the family caregiv-

ing experience and concluded that two aspects of recovery are relevant - family's provision of recovery-oriented support to an individual, and secondly, as the family's own recovery journey. We have suggested that the individual's recovery journey is mirrored by a recovery journey of other family members. They also need to rebuild supportive connections which are threatened by the emergence of illness. They need to exercise a sense of agency and autonomy, making difficult decisions about their own welfare as well as that of a recovering family member. Hope and meaning making are critical concepts for the family too. For people with mental health distress it is about taking charge and finding meaning in one's own life. For families it is about letting go of some caring responsibility or integrating the caring role as well as finding meaning in their own life. This work highlighted that while there were many similarities there were also points of tension between consumer and family recovery tasks. (Wyder and Bland, 2014). Table 1 illustrates how the different recovery tasks apply to each of these roles.

In 2019, we had a series of guided conversations with carer peer workers at Wellways, (Victoria) around the strengths and limitations of using the recovery

Table 1

Family based recovery model.

Principles of recovery	Consumers' recovery	Recovery oriented care-giving	Families recovery
Connectedness	Being connected to self, others and community	Supporting loved one to feel connected	Remaining connected to self, others and community
Hope and Optimism	Belief in the possibility of recovery	Finding ways to support loved one to maintain hope	Maintaining hope for own life
Identity	Redefinition of self Overcoming stigma and shame	Redefinition of relationship with loved one	Redefinition of caring role in own life. Overcoming stigma and shame
Meaning in life	Making meaning of experience with mental illness.	Balancing limitations imposed by the illness while allowing their loved one's strengths to shine.	developing a life that extends beyond the caring role
Empowerment	Personal responsibility and taking control over life	Supporting consumers to take control while allowing them to take risks and fail.	Assuming control over own life

framework to describe the family experiences. As a result, we proposed a shift of focus from the family as *a whole* to the impact and interactions on the individual family member. This framework acknowledges how the impact on each person in the social network. It highlights that a person's ability to provide support, and that their reactions to the stressors and resources are dependent on their experiences, their social circumstances, internal resources as well as vulnerabilities. Families are seen as interdependent of one another and there is a complex interplay between the various stressors people experience, and their abilities to cope (Wyder et al., 2021).

Such a relational approach does not dismiss the focus on the uniqueness of the recovery journey or the primacy of the individual experiencing the mental health distress. Instead, it refocusses the attention on the relational context, interactions, and relationships between different members of the social network. Relational recovery encourages a more inclusive approach which seeks to empower all parties. It places the experiences of the mental health crisis and recovery within the social context and networks of the person. This repositioning also allows us to address the consequences of the experiences. Many behaviours which can be associated with an illness such as psychosis can impact on the person's relationships with their social networks. Lastly, a relational approach, where people have multiple identities and hold multiple roles, refocuses the attention from a one-way caring relationship (where one person provides the emotional and practical support to another) to a two-way relationship based on care and love. This acknowledges that the role of families is more than that of "providing care" and emphasises the complexity of family relationships.

While the recovery framework has obvious strengths and the CHIME recovery processes are highly relevant to the individual and families involved, it does not acknowledge the profound impact of the mental health crisis on people and their families. The social inclusion model highlights the impact of these (i.e. poor housing, impact of the caring responsibilities on a person's employment options, poor health or the family's experiences of social isolation). Furthermore, the experiences of grief, loss and trauma, which has been well described in the literature are also not acknowledged (Wyder et al., 2021). A recent, best fit analysis of the literature noted that the five CHIME processes encapsulate the majority of recovery experiences but that these were not sufficient to capture all of the experiences. Most notably the theme of Difficulties experienced and that and expansion to a CHIME-D (D for difficulties) was needed (Stuart et al., 2017). We propose that this extra dimension is relevant for understanding the family experience of recovery. By not acknowledging the grief loss and trauma for families an important dimension is missed. The model shows the typical dimensions of recovery when applied to the person with a mental illness, and then

two ways of considering family connection with that phase of recovery: families as supporters of the recovery of an individual family member, and the family recovery journey in its own right. The theme of managing distress and trauma applies across all dimensions of recovery.

Changes of recovery over time

For many families, the experiences of grief, loss and trauma can be cumulative and most importantly ever changing. It is generally acknowledged that recovery is as a non-linear journey and several authors have proposed that a person's recovery process involves a process of early, mid and later stages and that the experiences of recovery are qualitatively different at different times in a person's life. Experiences of illness are not static and what might be important for an individual at one time maybe different later in life. (Hancock et al., 2018), In related rcovery research, some frameworks have been developed to capture the experiences of the carers over time. Generally, these frameworks focus on different phases of the illness. The Carer Life Course Framework is one such framework (Pagnini, 2005) and identifies six phases of caring that most carers work through. These include noticing changes, confirmation, surviving, managing, thriving, and life after caring. It is noted that the experiences are often cyclical. People can also move in and out of the different phases. Our own work however suggests that for families these changes are experienced as dynamic and cyclical and often in response to what is happening with their loved ones (Wyder et al., 2021).

The everchanging experiences of recovery for the person and the family are important to acknowledge as this implies that the different recovery processes of connectedness; hope and optimism about the future; identity; meaning in life; and empowerment also change and that when the needs of the person living with the mental illness change, the experiences of the family change as well. For example, Hope, which is central to recovery is important in different ways at different stages of the recovery journey. At the time of first episode of psychosis, the family member might reasonably hope for restoration of full mental health. If this doesn't happen and a more enduring form of illness persists, the parent might hope for more modest outcomes – that the person can lead a satisfying life despite the illness, or even that the family can cope well with whatever happens.

While these general frameworks for family recovery can provide some guidance as to how the recovery experiences change for families, there is a real need to further investigate not only how families adapt, manage and respond to the illness but more importantly the impact of these on their well-being and their needs for support during these times. There is limited understanding as to how

families adjust to the ever changing and cycles of the illness. It is likely that families experience what could be called "emotional touchpoints" not only with services but also in relation to the illness and their relationships with their loved ones. Such touchpoints can be defined as moments or processes where we are touched emotionally (feelings) or cognitively (deep and lasting memories) and are often referred to as important moments or turning points. Understanding these would allow us to have a more nuanced approach to providing support to families who may be at different stages in their recovery journey.

Families are in a unique position to offer hope and encouragement, and are often challenged to support the independence, decision making and autonomy of the individual. Working with families through a relational recovery framework is important and demanding work that demands patience and a commitment to the process. A psychotic illness in the family can impact not only on the family dynamics and relationships, and while for many family relationships are strengthened over time, others can experience relationship break down for a variety of reasons. This suggests that, particularly during times of crisis, where relationships can be fractured, there is a need for relational healing. Mental health workers might well adopt a focus on supporting the whole family, rather than just an individual.

Families are seen to have a role in supporting the recovery journey of the individual. They are able to provide much of the connection and relationship within which recovery happens. Both a social inclusion perspective, and a recovery perspective, offer helpful ways of thinking about the family experience of mental health crises. The dimensions of social inclusion, and their measurement, add additional rigorous empirical evidence for the impact of serious mental health problems on the family. Recovery theory, and particularly the understanding of relational recovery, offers a framework for considering the personal and social dimensions of the family experience.

Conclusions

Social inclusion and recovery, while developing from different starting points, converge in recognizing the broader personal, family and community contexts, in which mental health problems emerge, and the impacts of those problems. They offer clinicians and policy makers a range of points of intervention to address these serious negative impacts. A significant part of the context for recovery and measures to achieve social inclusion, remains the person's family. We are encouraged to explore further the nature of family support, the family's journey of recovery, and the changes to family experience over time.

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