Rethinking Hope and Work in Psychosocial Rehabilitation: A Case Study from Bangalore, India

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Abstract

In this thesis I present a person-centred ethnography of the 'work of hope' in a psychosocial rehabilitation (PSR) centre for people with schizophrenia and/or bipolar disorder in Bangalore, India. The thesis is structured around a critique of three shortcomings in the psychosocial rehabilitation (PSR) literature: first, the overly monotonic, positive inflection of hope; second, the narrow, rigid definition of 'meaningful' work as full-timed, waged labour; and third, the overly individualized conceptualization of hope as a purely internal emotional state. As I show, hope is an emotion that is developed, nurtured, and sustained by many people within the therapeutic community—not just the residents. Similarly, due to its cultural significance, 'work' (understood as full-time, waged labour) is the object of many PSR clients' hopes, and many rehabilitative and therapeutic activities are vocation-oriented. However, a number of clients expressed more nuanced visions of what 'meaningful work' meant to them. Such narrow conceptualisations of hope and work—both of which serve as central constructs in therapeutic settings—are problematic because they fail to consider the person- and context-specific ways in which these terms are defined. 'Meaningful work' need not entail waged labour and could involve different activities, such as volunteering. Furthermore, the work of hope in PSR is laden with equally compelling negative emotions, such as fear, dread, and pessimistic fatedness. Hope is not just an individually-based emotion; it involves socially distributed emotional labour to create and sustain hopefulness among PSR service users.

Declaration

This thesis is my own work, and has not been submitted for a higher research degree to any other university or institution. All sources used have been acknowledged.

Ethics Committee approval has been obtained from both Macquarie University (protocol number 5201500065) and the Richmond Fellowship Society (India), Bangalore branch.

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Introduction

Psychosocial rehabilitation (PSR), also known as psychiatric rehabilitation, is a steadily expanding mental health service in urban India that was developed during the 1960s and 1970s alongside the deinstitutionalisation and decentralisation movements in American mental healthcare (Anthony 1993; Turner and TenHoor 1978). PSR's primary objective is to ensure that persons with mental illnesses are able to function in society as seamlessly as possible. Although not all mental illness can be 'cured,' its consequences can be minimised to ensure people are capable of living independently and pursue their aspirations (Anthony 2000; Anthony et al. 1983). One example of a PSR approach is Therapeutic Community, a community-based method known for its democratic, non-hierarchical and behaviourist stance on rehabilitating persons with severe mental illnesses such as schizophrenia (Campling 2001; Rapoport 1967). Since 1972 when the first PSR centre in India was established, PSR principles and practices have become widespread in urban areas such as Bangalore and New Delhi (Murali and Rao 2004). PSR's emphasis on assisting persons with mental illnesses to have the capacity to live independently has resonated with mental health service providers and users, leading to its increasingly widespread usage.

However, PSR's North American cultural biases are noticeable when examining how Indian PSR facilities operate. The majority of assumptions built into psychosocial rehabilitation practices come from American individualism: emphasizing full-time, waged labour above all other forms of employment; attributing the source of illness to the individual; framing PSR service users as people incapable of productively contributing to society (Estroff 1993, 1995:88-90). Hope as a key catalyst for recovery in the PSR literature also has American individualist values embedded in it, because the process – 'work' – of cultivating hope is portrayed as a strictly individual process. This fails to account for the contingent nature of hope, and how a person's social surroundings can cultivate or frustrate hopeful attitudes (Crapanzano 2003; Deegan 1988; Russinova 1999). North American cultural biases have distorted how PSR practitioners understand the 'work of hope,' and this needs to be thoroughly questioned and analysed. Even though several psychosocial rehabilitation centres exist in countries such as India — thus potentially attesting to the validity of its principles in urban Indian settings — it is nonetheless important to question how psychosocial rehabilitation methods' in-built assumptions can lead to limitations in the rehabilitative process.

The central theme of this thesis is the 'work of hope' in psychosocial rehabilitation (PSR) for schizophrenia patients in an urban Indian context, and critiquing three assumptions frequently held within the PSR literature surrounding the rehabilitative process. Estroff's (1995) criticism of psychosocial rehabilitation has two key aspects: 1) PSR practitioners' neglect of their clients' subjective illness experiences; 2) the narrow, myopic definition of 'work' in PSR contexts as full-time, waged labour. I intend to expand upon these points by addressing another shortcoming in the PSR literature: the monotonic, overly positive and individualistic portrayal of hope. The psychological benefits of cultivating a hopeful attitude throughout the treatment process have been documented by schizophrenia patients such as Deegan (1988) and Schiff (2004) and PSR practitioners such as Russinova (1999). However, my observations of 'Asha,' a PSR 'halfway home' in Bangalore, India indicated that hopeful optimism was not the only emotion being expressed among residents. Negative emotions such as fear, dread and pessimistic fatedness — feeling like one is destined to stay in PSR centres forever — proved to be equally influential and commonplace. I will unpack, analyse and elaborate further upon these issues, thus demonstrating that 'hope' and 'work' as they have hitherto been portrayed in the PSR literature fail to provide a holistic account of the schizophrenia recovery process.

This thesis will adopt a person-centred ethnographic approach in its examination and analysis of hope and work's complexity in PSR settings. Person-centred ethnography attends to the ways an individual's subjective experience shapes, and is in turn shaped by, their social and cultural environments (Hollan 2001). Although structural factors certainly are influential, they do not always represent an individual's subjective experiences, nor completely determine people's actions and thoughts (Mattingly 2010:47). The act of hoping generally starts with individuals, but the realisation of hopes is contingent on external entities such as chance as well as other people's actions. We can only do so much to accomplish our hopes, because we are ultimately dependent on circumstances beyond our control (Crapanzano 2003). In order to find out the relationship between the individual, their surroundings and beliefs, person-centred interviewing alternates between treating the interviewee as a respondent and informant. Interviewees are at once sources of information for the interviewer ('informant'), as well as individuals who are encouraged to articulate their distinct (and often idiosyncratic) subjective experiences and opinions, exploring how their past experiences influence their current actions and thoughts ('respondent'). Additionally, the interviewee's body language during the interview is analysed in order to scrutinise the interviewee in their entirety, and not just their verbal representations (Levy and Hollan 1998). Person-centred ethnography is therefore a suitable methodological approach for this thesis due to its emphasis on examining the interdependence between people's subjective experiences and their surroundings.

In order to demonstrate the varied ways in which PSR service users conceptualise 'hope' and 'work,' I will cite excerpts of self-narratives created by participants in their semi-structured individual interviews and focus group discussions. Persons with chronic and/or terminal illnesses have frequently relied on (re)creating narratives to maintain their psychological wellbeing, recreate new self-identities, and hopefulness for convalescence (Becker 1997; Good et al. 1990, 1994; Mattingly 2010). Self-narratives therefore are shaped by, and shape, a person's self: when people imagine their ideal future selves, they start planning ways to actualise these images in everyday life. In doing so, they devise methods and goals with an overarching objective to actualise what they have imagined. This is akin to creating and structuring a plot with a beginning, middle and end. People's notions of self are thus constructed and lived by using narratives (Bruner 1987, 1991). The process of 'therapeutic emplotment' helps PSR service users and providers collectively organise and structure rehabilitative activities to embed the service user's aspirations into said activities (Mattingly 1994). Emplotment is important for schizophrenia patients because their functionality is constantly at risk of disappearing when relapses occur (Birchwood et al. 2000). The Asha residents I observed made a concerted effort to create plans to actualise their hopes, as this helped them remain optimistic about the rehabilitative process. Creating self-narratives not only has the potential to help these patients understand and communicate their illness experiences, but also to re-establish and (re)present themselves to other people.

Psychiatric literature has largely dismissed schizophrenic narratives on the grounds of their unintelligibility, but this is not always applicable to mild to moderate cases (not acute or treatment resistant) of schizophrenia. Unsurprisingly, psychiatric research on schizophrenia has near-universal agreement on the profound disruption of selfhood patients experience (Lysaker and Lysaker 2002:207-8): the chemical imbalances in schizophrenia patients' brains are assumed to render their self-narratives meaningless and lacking in cohesion. Indeed, schizophrenia patients are understood in the psychiatric literature to be largely insentient, 'people' whose emotional and speech processing capacities are completely determined by neurological malfunctioning (Estroff 2004). One example of this is 'flat affect,' where schizophrenia patients are unable to recognise emotions from facial features and encounter difficulties in expressing socially appropriate emotions, verbally or otherwise (Gur et al. 2006; Mandal et al. 1998). However, such debilitating depictions of selfhood and individual agency do not always apply to mild to moderate cases of schizophrenia patients. In fact, schizophrenia patients can regain self-confidence and a sense of self by (re)constructing their self-narratives, in order to provide continuity between their pre- and post-illness lives and envision their future selves (Roe and Davidson 2005). Since it is up to the schizophrenia patients to do the re-constructing, if we wish to aid the recovery process we need

to respect and listen to them.

Asha's transparent, inclusive procedures and respect for its residents' opinions made it a suitable place to investigate the issues I will discuss in this thesis. Asha adopts Therapeutic Community principles: minimisation of hierarchy, democratic decision-making, reality confrontation and permissiveness (Rapoport 1967). These values form the crux of the 'living-learning' experience, involving the usage of everyday activities for therapeutic and rehabilitative purposes (Campling 2001). Residents typically stay from 6 to 24 months, and are taught time management skills, money management, personal hygiene and adherence to routines. Through undertaking such 'everyday' activities, residents regain self-confidence and learn about Indian societal norms. Unlike psychiatrists and medical professionals who essentialize schizophrenia patients as persons whose neurological problems render them devoid of individual agency (Estroff 2004), Asha respects and values its residents' decision-making abilities. Prospective residents are only admitted when they provide explicit verbal consent; forced admissions are forbidden. Except for daily briefing meetings in the morning, Asha staff maintain an 'open door' policy for residents to come in whenever and share their concerns, Asha-related or otherwise. These procedures exemplify Asha's commitment to listening to its clients and valuing their opinions, making it a well-reputed PSR centre in India.

Having noticed Asha's inclusive stance towards its residents, I conducted fieldwork to examine the ways in which Asha residents learned how to create and sustain hope, and to identify their definitions of 'meaningful work.' The pilot study was qualitative in its focus. Over a three-month period between June and September 2015, I worked with 7 out of 12 Asha residents who were selected on therapist referrals. I conducted participant observation for the first two months, followed by semi-structured individual interviews and two focus group discussions during the last month of my stay. All interviews and focus groups were audio and video recorded, and data was transcribed and coded using *NVivo*. No Trial Stay residents (prospective residents undergoing a two-week stay in Asha to determine whether they want to continue staying or not) were asked to participate, and all participants provided written and oral verbal consent. Ethics approval was obtained from both Macquarie University, and the Richmond Fellowship Society (India), Bangalore branch. Asha's emphasis on obtaining explicit verbal consent from prospective residents and usage of English as its preferred language of communication meant the interviews and focus groups proceeded seamlessly. All participants understood the interview questions, and focus group participants managed to successfully facilitate one focus group independently without my involvement.

The first chapter of this thesis examines the psychiatric literature's viewpoint on schizophrenia patients' (in)ability to generate coherent self-narratives, and provides a brief overview into the origins of psychosocial rehabilitation and decentralisation movements in Indian mental health policy. Based on observations of Asha residents, I argue persons with mild to moderate degrees of schizophrenia (not acute or treatment resistant) should be encouraged to create and share their self-narratives in order to (re)create their self-narratives in a public setting and work towards their future projections. Chapter 2 addresses the tensions between hope, fear, dread, and pessimistic fate. Various combinations of these four emotions will be provided from Asha residents' self-narratives to highlight the fragile and volatile aspects of the recovery process. Chapter 3 builds upon Estroff's (1995) criticisms of PSR — its inadequate, narrow definition of 'meaningful work' and the presence of American cultural biases in PSR methods — by discussing the ways in which Asha residents define their motives for employment. In Chapter 4, I argue that hope is not an emotion generated solely by individuals, but is in fact a collective effort involving socially distributed emotional labour. A conclusion of the thesis then follows.

Chapter 1: A Brief Overview of Schizophrenic Narratives, Mental Health Policy and Psychosocial Rehabilitation in India

Psychosocial rehabilitation (PSR) was influenced by deinstitutionalisation movements in American mental healthcare during the 1960s and 1970s, and has spread overseas due to its demonstrated effectiveness in rehabilitating persons with mental illnesses. In this chapter I argue that the monolithic, bleak portrayal of schizophrenia patients in the psychiatric literature from the mid-late 20th Century inaccurately conveyed the functionalities of people with mild or moderate schizophrenia. While people with acute or treatment resistant schizophrenia were highly unlikely to regain their sense of self, this was not always the case for patients with less severe symptoms. In response, deinstitutionalisation and decentralisation of mental health services were proposed by practitioners to introduce a more humane, inclusive and effective form of mental healthcare. Community-based mental health services were proposed as ideal replacements in the United States, and psychosocial rehabilitation (PSR) is one example of this. A similar transition was also occurring in India from the 1980s with the introduction of the District Mental Health Plan (DMHP), when Government of India policymakers recognised the budgetary and infrastructure constraints of providing affordable, quality services from its mental health hospitals. To meet the growing demand for accessible mental health services, non-government organisations such as the Richmond Fellowship Society (India) (RFS(I)) established PSR centres. Asha is the RFS(I) Bangalore branch's 'halfway home,' designed as a transitional place for persons with schizophrenia and/or bipolar disorder to learn vocational skills and develop traits to help them socialise and assimilate into mainstream society.

Schizophrenic Self-Narratives in the Psychiatric Literature

Despite contestations surrounding schizophrenia as a disease category and its symptoms, almost all psychiatric literature concludes that schizophrenia patients often experience a severe, debilitating loss of self. This is however qualitatively different from existential concerns surrounding one's role or purpose in life. Instead, it is a disintegration of self-identity and the subsequent inability to rearrange its remnants coherently (Lysaker and Lysaker 2002). As a result, many schizophrenia patients have difficulty realising that they are schizophrenics, whereas other people will notice immediately based on the patients' behaviour. 'Poor insight' is thus one of the

hallmark features of schizophrenia patients, and also a key indicator in poor treatment compliance (Lysaker et al. 2002). Schizophrenia patients have also been reported to be incapable of identifying, understanding and expressing emotions through verbal communication or facial features — this is known as 'flat affect' (Gur et al. 2006; Mandal et al. 1998). Perhaps the most concerning feature about schizophrenia is its seeming inability to be 'cured': the complete elimination of its symptoms from the organic body. Even with effective pharmacological and psychotherapeutic interventions, the possibility of a relapse cannot be completely eliminated, and patients must remain on treatment for the rest of their lives (Birchwood et al. 2000). The combination of the aforementioned features of schizophrenia places patients in a difficult position when they attempt to generate well-structured and defined self-narratives in order to understand themselves and their illness experiences.

This made the possibility of schizophrenia patients creating coherent self-narratives unlikely, and explains the relative lack of existing scholarship on analysing schizophrenic narratives. In contrast, self-narratives of people with somatic terminal and/or chronic illnesses (such as infertility or cancer) have been extensively examined to analyse how these patients attempted to make sense of their illness experiences (Becker 1997; Good et al. 1990; Mattingly 2010). As Jerome Bruner (1987, 1991) argues, life is organised and lived as narratives, a set of events thematically linked together – the 'plot.' Instead of providing chronologically coherent and all-inclusive stories in autobiographies, people will restructure them using selective memory because recollections of lived experience are culturally mediated cognitive exercises (Bruner 1987:12-3). Additionally, the subjunctive quality of narratives is important, because it helps people imagine ideal future scenarios, and start considering how they can reproduce said scenarios in everyday life as accurately as possible. In other words, people become the narratives they recite to others by experiencing life as it happens through the very narratives they have constructed (Bruner 1991). The process of creating narratives thus helps patients with chronic illnesses establish coherence from the disconnection occurring between their pre-onset and post-onset notions of selfhood, while medical professionals frame the treatment process using narratives to maintain the patient's psychological wellbeing and optimism (Becker 1997; Good et al. 1994). Narratives are the primary means through which people experience and describe their lives, while guiding themselves towards their ideal future selves.

Mild to moderate degrees of schizophrenia however did not hinder people's abilities to generate coherent self-narratives as adversely as the psychiatric literature had suggested. Estroff's (2004) correspondence with schizophrenia patients revealed their anger towards psychiatrists' adoption of biomedical determinism. The patients felt that medical professionals did not regard them as

sentient people with individual agency, but as people whose thoughts and actions were completely deterministic to neurological problems. Questioning such instances of biomedical determinism, Roe and Davidson (2005) and Ridgway (2001) argue that the aforementioned analyses of schizophrenia patients from the previous section are not always applicable to mild or moderate cases. In fact, most of their research participants were capable of organising ideas and thinking coherently. Encouraging schizophrenia patients to re-author their life stories and illness experiences proved to be beneficial in their recovery processes because it was an opportunity for patients to recreate and provide direction in their sense of selfhood (Roe and Davidson 2005:92-3). Similarly, Corin et al. (2004) and Lucas (2004) reported that in their respective research sites – India and Australia – schizophrenia patients relied heavily upon cultural tropes and symbols to communicate their experiences of psychoses. The patients were capable of generating self-narratives by relying on their physical and social surroundings, albeit with varying degrees of coherence. This suggests that psychiatrists have hitherto overly relied on existing scholarship when interacting with clients, instead of actively listening to them and their self-narratives to evaluate their cognitive abilities.

The Origins of Psychosocial Rehabilitation and Therapeutic Communities

Psychosocial rehabilitation (PSR) was developed in line with the introduction of deinstitutionalised mental healthcare in the United States from the 1960s and 1970s, with influences from physical rehabilitation. The National Institute of Mental Health introduced the 'community support system' (CSS) during the mid-1970s, after identifying failures in deinstitutionalised mental health services for persons with severe and persistent mental illnesses (Anthony 1993:522). The bulk of the criticisms towards deinstitutionalised services targeted a lack of demonstrated improvement from its service users with recurring symptoms and visits to psychiatric hospitals, no institutional support to provide disability support income, and the usage of unclear treatment goals (Anthony et al. 1983; Turner and TenHoor 1978). In response, PSR was influenced by CSS in its agenda to create communities of caregivers whose services meet the needs of its users and helped nurture their aspirations (Anthony 1993:523, 2000). Additionally, the concept of physical rehabilitation influenced PSR: similar to how patients with spinal cord injuries are not 'cured' but instead learn how to adapt to their condition, PSR used a mixture of psychotherapy techniques and pharmacological interventions to help clients manage their psychoses (Anthony 1993; Anthony et al. 1983). PSR intended to reproduce the fundamental principles from physical rehabilitation, but translate them into appropriate interventions for

persons with mental illnesses in community-based settings.

Within PSR, the 'recovery' approach towards rehabilitation has been the de facto model adopted since the 1990s. Broadly speaking, mental health service providers agree that severe mental illnesses such as schizophrenia are not 'cured,' but 'contained.' The recovery model therefore involves service providers teaching their clients how to accept and continue living with their illnesses by gradually developing relevant skills to achieve their aspirations in life (Anthony 1993:524-6, 2000; Liberman and Kopelowicz 2005; Spaniol et al 2002). Schiff's (2004:215) definition of 'recovery' has three primary features: 1) a recovery of one's 'internal self,' 2) a recovery of one's social role, and 3) the ability to function comfortably in one's surroundings. This is a more holistic approach than a strictly biomedical definition of 'recovery' (which tends to emphasise 'cure'— the partial or total elimination of organic dysfunction from the body of the sufferer), and is better suited towards addressing schizophrenia's negative symptoms. All three dimensions of Schiff's model of recovery are addressed by **PSR** professionals. For example, Asha staff spend 5 to 10 minutes at the end of every activity to ask residents for their feedback, encouraging them to develop and share their opinions. In a 'living-learning' environment, incidents that arise from interactions between residents serve as opportunities for them to learn social etiquette (Kennard 2004). By being completely immersed[1] into house activities, residents gradually become comfortable in their social surroundings, which in turn makes their rehabilitative experience more fulfilling.

One of the key features of **PSR** is social skills training, which is designed to introduce and educate clients on social norms and self-management skills. The so-called 'negative symptoms' of schizophrenia (such as lack of motivation, inability to process and express emotions verbally or through body language, and reluctance to interact with other people) hinder sufferers' attempts to live independently from the hospital and their families (van Os and Kanpur 2009). In response, PSR service providers teach their clients 'social skills' such as general etiquette, negotiation, and money management. Once clients are adequately trained and familiar with social skills, it is expected that they are capable of interacting with people across a wide range of everyday settings such as the supermarket, school and workplace (Kopelowicz et al. 2006). For example, Asha staff provide money to residents to make weekly snack purchases. Each resident is responsible for buying snacks of their choice, and bringing back correct change and the receipt. The staff trust all residents to make responsible choices such as not buying high-fat/sugar snacks. When residents purchase overly sweet snacks or forget to bring back the receipt, staff will educate (but

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[1] This process is similar to Lave and Wenger's (1991) concept of 'legitimate peripheral participation.'

not punish) them by providing reminders. Developing schizophrenia patients' skills and abilities to adapt to various situations serve as cornerstones in PSR due to its emphasis on reintegrating clients back into their communities. PSR is structured around everyday activities because it is precisely those tasks that schizophrenia patients frequently struggle to understand.

The Therapeutic Community model provides an ideal template for PSR's main principles: emphasis on vocational and social norms training, a recovery-oriented approach towards rehabilitation, and community-based services. Therapeutic Communities were originally developed in the United Kingdom[2] as a 'Social Rehabilitation Unit' in a hospital where staff and patients collectively designed a treatment plan for all 'residents' (Rapoport 1967). Socialisation and group activities comprised the bulk of the activities in the treatment scheme, with tasks such as resident-facilitated weekly community meetings. These meetings were run by residents in order to encourage them to resolve conflicts and develop socialisation skills independently without staff interventions (Whiteley 2004). Through continued interaction with fellow residents, staff hoped that residents would build tolerance for differing opinions, involve others in attempts to change their own self-image, develop better communication skills and actively participate in group activities. These goals represent the four key tenets of Therapeutic Communities: permissiveness, democracy, reality confrontation and communality (Campling 2001; Kennard 2004). Therapeutic Community is therefore an ideal treatment modality for PSR facilities to adopt due to its emphasis on group activities, inclusiveness, and using residents' embodied experiences as learning opportunities.

The Push for Decentralisation in India: A Brief History

In a similar period of time — mid to late 20th Century — when the deinstitutionalisation of American mental health services occurred, the Government of India (GoI) also started transitioning to a community-based mental health system[3]. The Bhore Committee was established in 1946 to address key concerns in the healthcare system, including the mental health sector. The Committee's report argued that the then-current institutional model of mental healthcare was inadequate in meeting the needs of rural populations, and suggested an expansion of primary

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[2] It is important to distinguish between the English and American variants of Therapeutic Community: the former entity involves community members — 'residents' — actively involved in the daily operations of the Therapeutic Community, whereas the latter variant describes a hierarchically structured community targeting substance abuse (Campling 2001).

[3] Decentralisation initiatives already started from the 1920s in India, when the British government changed the primary objectives of mental hospitals from custodial care to symptom alleviation and recovery. Government asylums were referred to as hospitals from 1920, and occupational therapy was introduced during the 1930s in order to keep patients engaged in 'productive' tasks such as tailoring and carpentry (Menon 2004:33; Sharma 2004:28-9).

care infrastructure in remote communities (Menon 2004:31). Consequently, the National Mental Health Programme (NMHP) was introduced in 1982 to accomplish three objectives: 1) to ensure basic mental healthcare such as counselling and psychopharmaceuticals remain available for all sections of the population, especially people from lower socio-economic backgrounds; 2) to integrate mental healthcare into general medicine; 3) to encourage participatory methods of mental healthcare in the community, and for communities to develop their own mechanisms for addressing psychological distress (Murthy 2004:76). Considering India's sociocentric tendencies, the GoI deemed community-based mental health interventions such as group counselling conducted by local villagers to be more effective than institutionalised healthcare in tackling depression, and other forms of psychological distress (Goel et al. 2004; Kapur 2004). Decentralisation and deinstitutionalisation were two key concepts in the NMHP agenda, intended to increase the coverage of mental healthcare to encompass rural areas, and decrease reliance on overcrowded and underfunded psychiatric hospitals.

In response to the Government of India's push for decentralising mental health facilities, non-government organisations started establishing psychosocial rehabilitation (PSR) centres to meet increasing demand for mental healthcare. According to Murali and Rao's (2004:151-3) overview on PSR in India, PSR was largely confined to government hospitals providing vocational activities for clients alongside occupational therapy from 1945 until the early 1970s. This was because medical staff in government hospitals noticed that anti-psychotic medication was useful in mitigating schizophrenia patients' positive symptoms (delusions and hallucinations), but their inability to comprehend and adapt to societal norms required activity therapy (Murali and Tibrewal 2008). Indian mental health professionals thus adopted a behaviourist approach towards psychosocial rehabilitation, which states that by undertaking meaningful tasks, people develop self-confidence and experience positive emotions such as happiness – 'doing' changes 'being' (Harvey-Krefting 1985). The professionals also recognised that PSR provided opportunities for the larger community to be involved in the rehabilitative process as volunteers or providers of supported employment schemes, thus encouraging service users to interact with 'normal' people (Murali and Rao 2004:154). The first non-governmental PSR facility was established in 1972, and there were approximately 50 PSR service providers in India as of 2004 (Murali and Rao 2004:153-4). Having recognised the potential benefits of behaviourism in rehabilitating people with mental illnesses, Indian mental health professionals expanded their secondary care services[4] to incorporate PSR as a means to help them learn and adjust to social norms and live within mainstream society.

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[4] Most Indian PSR centres require referrals from a psychiatrist for admission.

Asha: A Halfway Home

The Richmond Fellowship Society (India) (RFS(I)) was founded in 1986 to help integrate people with mental illnesses back into mainstream society and meet increased demand for PSR facilities in Bangalore. The RFS(I) is currently based in Bangalore, Lucknow and New Delhi, with an additional rural outreach centre in Sidlaghatta, Karnataka (RFS India 2016). The Bangalore branch has three PSR facilities: 'Chetana,' a daycare centre for persons with bipolar disorder, schizophrenia and/or learning disabilities; 'Asha,' a halfway home for persons with bipolar disorder and/or schizophrenia; and 'Jyothi,' the long-stay centre for clients who are transferred from Asha. All of the RFS(I)'s facilities adopt Therapeutic Community values (Rapoport 1967) because the staff thought inclusive and democratic means of group therapy was the most appropriate method for rehabilitation. Clients are admitted based on psychiatrist referrals, and prospective Asha clients — 'residents' — undergo a two-week Trial Stay. During this time, they are treated like other Asha residents, in order for them to learn about Therapeutic Community principles and familiarise themselves with house activities. An Admissions Committee meeting then takes place, where the Committee asks prospective residents to share their experiences of staying in Asha. Residents are only admitted into Asha only if they provide explicit verbal consent in the Committee meeting that they wish to stay.

Asha operates explicitly on individual consent and feedback provided by residents, in order to maintain a democratic, non-hierarchical style of managing a Therapeutic Community. Despite the problems surrounding the definition of a 'service user' in Indian mental health due to the heavy involvement of family caregivers (Srinivasan 2008), the Admissions Committee will only proceed with prospective residents if they provide verbal consent. Put succinctly, family members of prospective residents cannot forcibly admit them into Asha. The allocation of house duties such as sweeping the floor and cleaning the dining table is done once a week on Thursdays, when residents hold a community meeting to provide feedback to one another about their performances. All residents are expected to hold each other accountable, and are allowed to select the maintenance duties they wish to undertake for the upcoming week. Except for daily staff morning meetings, Asha staff maintain an 'open door' policy where residents are encouraged to visit the staffroom and share Asha-related or personal concerns at any time. Staff encourage— not force — residents to share their opinions, in order for them to identify every resident's needs and incorporate them into house activities.

Asha house activities mimic the daily routines of everyday life as much as possible to help

residents learn and familiarise themselves with the importance of structure and discipline. Residents wake up at 6 o'clock, exercise from 7 and have breakfast at 8:30am. From 9am until 10:30am, residents complete their house maintenance duties. From 11am until 12:30pm, there are various activities day to day. To provide two examples: on Mondays, residents will prepare their weekly medicines with staff supervision, and each resident is asked to place the right dosage and medication in their medicine containers. Tuesdays involve staff-conducted workshops on everyday activities such as diet, personal hygiene, and expressing emotions. Lunch is served afterwards until 1:30pm. Most residents attend afternoon classes at Chetana such as printmaking, embroidery, computer literacy from 2pm until 4:30pm. They attend evening exercise from 4:30pm until 5pm, after which they are free to do whatever until 7pm for dinner. All residents then go to sleep from 9pm. Monthly activities such as a movie outing, eating out at a local restaurant or a day trip are also included in the routine to provide variety and entertainment for the residents. Asha's mixture of a strict weekly schedule with intermittent leisure activities reproduces a typical daily schedule of 'normal' people working full-time. This teaches and prepares residents for managing their lives independently.

Due to Asha's emphasis on patient consent and individual agency as key conditions for admission, the majority of the residents were largely functional and able to socially interact with both staff and outsiders. In the pilot study, 7 out of 12 Asha residents participated. From the five residents who did not participate, two were functional but introverted and did not provide consent. Another resident was partially functional, but his delusions waxed and waned. When I started the individual interviews, his delusions were active and he therefore declined to participate. The remaining two residents were diagnosed with acute schizophrenia, and they were likely to be transferred to 'Jyothi.' Among the 7 participants, five of them completed a Bachelor's degree, while one participant completed a Master of Business Administration and two other participants attempted postgraduate studies. The two residents who did not complete tertiary education could converse seamlessly in English, and had plans to pursue further studies or full-time employment once they were discharged from Asha. These traits reflect the general requirements Asha implicitly imposes on prospective residents: functional enough to process experiences, capable of communicating in English, and with moderate to minimal displays of severe psychoses.

During fieldwork, I noticed that hope was a key emotion deployed by Asha staff when they developed treatment plans for new residents. Hope is an essential part of the human condition because it instils optimism among people. It is a medium through which they can imagine and actualise their ideal future selves. One could argue that the 'death' of a person's hopes is akin to the death of their futures, because they would be incapable of imagining their ideal future selves

and creating a path inscribed with meaning and purpose (Becker 1997:177). Hope is important because Asha is a 'halfway home' in two ways – temporally and physically. Since residents are expected to stay between 6 to 24 months, staff need to be aware of what residents hope to do once they are discharged from Asha, or at least help them discover and develop future aspirations. For residents, Asha is an intermediary point between 'the real world' with 'normal' people who have full-time jobs, families and lead lives in line with the urban Indian cultural life course (Mines 1988), and the psychiatric hospital where socialisation will only occur between fellow residents and medical professionals. It is a place in which they can prepare themselves for re-entering mainstream society by reconfiguring their ideal future projections to maintain coherence and continuity in their lives (Becker 1997). Asha is inherently a transitional place for its residents, and the activities that staff and residents undergo in order to cultivate and sustain residents' hopes – the 'work of hope' – is vital in ensuring successfully discharging residents.

Conclusion

Although schizophrenia patients do experience a profound loss of personhood and selfhood from their illness, the magnitude is not always severe for patients with mild or moderate cases. In fact, encouraging such patients to attempt reconstructing their self-narratives and undergo activity therapy helps them re-establish individual agency and a sense of purpose and direction in their lives. Deinstitutionalisation and decentralisation initiatives for mental health services during the mid/late 20th Century prompted the growth of mental health services such as psychosocial rehabilitation (PSR), which combines pharmacological interventions with group therapy and the usage of everyday activities for therapeutic and rehabilitative purposes. This makes PSR well-suited to meet the needs of schizophrenia patients who are reasonably functional but cannot effectively manage positive and/or negative symptoms, resulting in its expansion beyond the United States. Mental healthcare providers in countries such as India – whose government was also transitioning from a centralised, institutionalised form of mental healthcare to community-based services – noticed PSR's effectiveness and started establishing facilities, mostly in urban areas. Non-government organisations such as the Richmond Fellowship Society (India) adopted group therapy-based forms of PSR such as Therapeutic Community, whose principles emphasised individual consent, agency and dignity of schizophrenia patients. In the next chapter, I will address the first shortcoming of the way PSR literature portrays hope: a monotonic, overly positive interpretation of hope's role in the recovery process for schizophrenia patients.

Chapter 2: Hope and the High Stakes of Psychosocial Rehabilitation

Hope is a key emotion that guides and motivates people in their daily lives, and its importance is clearly reflected in the psychosocial rehabilitation (PSR) literature. Through the 'work of hope,' PSR clients learn how to understand their illness experiences, re-assimilate themselves into mainstream society, and establish continuity between their pre- and post-illness onset selves (Becker 1997; Deegan 1988; Schiff 2004). For schizophrenia patients whose notions of selfhood are often fragmented and seemingly irreparable, the state of hopefulness serves as a means through which they can attempt to re-establish and re-orient their self-identities (Lysaker and Lysaker 2002; Roe and Davidson 2005). This however is an incomplete representation of the 'work of hope' because negative emotions such as fear, dread and pessimistic fatedness are equally important in PSR clients' recovery processes. In this chapter, I argue that hope in PSR research is depicted in an overly positive, homogenous manner as hope is only understood for its uplifting traits. Such interpretations of hope fail to consider its double-edged nature as both a catalyst and hindrance in schizophrenia patients' rehabilitative processes. I will first discuss the 'work of hope,' which represents the activities PSR service providers and users undergo to generate and maintain hopefulness and optimism among residents. The chapter then proceeds to provide ethnographic examples from Asha that demonstrate how hopes are in fact volatile and laden with negative emotions such as fear, dread, and pessimistic fatedness.

The Work of Hope

Hope is a fundamental human emotion that provides people with optimism in situations of desperation or despair, due to its future-orientedness that relies upon faith in external circumstances. Hopes help people to imagine their idyllic lives and attempt to realise them in everyday life, like a 'waking dream' (Desroche 1979:12-16). In particular, religious belief systems extensively rely upon hope, as seen by Judaeo-Christian religions' use of hope to encourage its adherents to maintain their faith in Christ until Judgement Day arrives. Hopes therefore contribute towards religious people's psychological stability by helping them maintain belief for salvation (Crapanzano 2003). Hope is culturally contoured and context-specific: while Americans thought of hope as a transient emotion used to help people stabilise their lives amidst periods of uncertainty or crisis, Koreans conceptualised hope as a permanent, long-term ideal used by people to guide themselves into the future (Averill et al. 1990:85). In medical settings such as

oncology wards, hope is used to incentivise treatment and to maintain patients' psychological wellbeing (Good et al. 1990). Due to the uncertainty that the future brings in people's lives, they rely upon the act of hoping in order to provide stability, continuity and coherence in their thoughts, beliefs and actions.

Similarly, hope is understood in psychosocial rehabilitation (PSR) contexts as a key catalyst in the recovery process for its clients, and rehabilitative activities are structured using the 'work of hope.' Hope in American — and by extension, PSR — settings is primarily understood as an individual-driven emotion. Starting with the American Dream, Americans have been conditioned to believe in themselves 'against all odds': when people exert individual effort to its highest level, nothing is impossible (Mattingly 2010:15-6). Similar sentiments of unwavering optimism are found in Russinova's (1999:51) discussion of hope in PSR recovery process as an agent of personal empowerment. In this case, hope serves as a 'guiding light' that motivates schizophrenia patients to imagine their ideal future selves, and to actualise these ideal selves by undergoing therapeutic and rehabilitative activities. By cultivating a hopeful attitude, PSR clients begin to understand their symptoms and illness experiences positively (Deegan 1988). Recovery thus becomes a part of the 'work of hope' through which clients, building on their daily successes and tribulations, recognise their capacities and 'work' towards re-integrating into one's surroundings (Liberman and Kopelowicz 2005; Ridgway 2001; Schiff 2004). Although recovery as a concept remains vague in terms of practical measures, it is generally understood as an uplifting attitude that helps PSR clients change their self-image and understanding of their illness experiences (Anthony 1993; Bachrach 2000). The 'work of hope' is thus presented as a vital instrument in PSR contexts for schizophrenia patients to exert their individual agency through unbridled optimism, largely following in line with American cultural values.

Such portrayals of hope however provide an incomplete picture of the recovery process, which is often marred with negative emotions such as fear and dread. Desroche's (1979:19-21) description of hope as 'exuberant expectation' illustrates the tension between optimism and pessimism among hopeful persons. For every instance where people's hopes united and motivated them to work together and realise their aspirations, there are just as many examples where hopes have discouraged and inhibited people. Hopes are therefore fragile, and their realisation is almost always contingent on external entities (Crapanzano 2003). For example, working class African-American families of children with terminal and/or chronic illnesses can only do so much to ensure their children receive medical attention. The healing process these children and their parents embark upon is paved with multiple interpersonal tensions and friction zones across different cultural, socio-economic and physical settings. For example, friction can

exist between parents and medical staff due to incompatible interpretations of a situation concerning 'good' healthcare and parenthood. What might be understood as proactive parenting and dedication by the African-American parent by sending her child to the emergency ward for a seemingly non-emergency issue could easily be perceived by medical staff as aggression, over-involvement and waste of resources (Mattingly 2010:100-105). Such moments of 'borderland trouble' represent the struggle these parents endure in order to create a life worth living for their children. The parents of these children can be as hopeful as they want and substantiate their hopes by taking action, but their children's fates are decided by a multitude of circumstances beyond their control.

Discussing the role of fatedness is also relevant when explaining the tension PSR clients face (especially schizophrenia patients) between a state of hopefulness towards restoring individual agency and feeling confined to life in PSR facilities until death. As discussed in Chapter 1, the possibility of relapsing serves a constant reminder for schizophrenia patients of the fragility they must endure in their lives. For schizophrenia patients whose functionality and cognitive stability waxes and wanes, not only can they lose their sense of purpose and direction in life, but also their ability to create and recognise notions of personhood (Lysaker and Lysaker 2002). Schizophrenia patients categorised as 'treatment resistant' have been exposed to all pharmacological and psychotherapeutic interventions, but their symptoms remain persistent. For such people, it is unlikely that they will ever regain a sense of self (Elkis 2007). Additionally, many persons with mild to moderate schizophrenia also struggle with understanding the idea of selfhood during the early stages of rehabilitation. This has clinical implications because schizophrenia patients are less likely to be treatment compliant if they themselves are not aware of their schizophrenic behaviour (Lysaker et al. 2002; Roe and Davidson 2005). The 'work of hope' is fragile for many PSR clients, who undergo daily rehabilitative activities in an attempt to progress towards a future that may never actualise. Schizophrenia patients in particular face severe difficulties in the recovery process due to the constant threat of relapse, and their inability to recognise themselves and organise their thoughts coherently.

Therefore, examining the moral and personal circumstances of each PSR client is important in order to determine their motivations and the stakes at play in their recovery process. The moral dimension of illnesses is a well-treaded topic in medical anthropology that addresses the subjective illness experience of the sick individual. Chronic illnesses represent a permanent disruption or 'derailment' of people's life aspirations and futures. For example, in an American cultural context, the loss of individual agency is a common source of grief and anger among patients with chronic and/or terminal illnesses (Becker 1997; Kleinman 1988). Illnesses

jeopardise patients' individual agency, and derail the possibility of achieving their aspirations if they cannot regain their functionality. There is much at stake for the patient's notions of self and psychological wellbeing if they do not convalesce completely (Kleinman 1999). It is therefore important to identify sick individuals' aspirations and sources of happiness prior to the onset of illness, so that medical interventions can be better adapted to their needs. While biomedical or socio-cultural models have significant explanatory power, neither of the models completely represent the individual's subjective experience (Kleinman and Kleinman 1991). Identifying what the illness means to the person's notions of a meaningful existence and life experiences (while acknowledging the influences of their cultural backgrounds) provides more nuanced understandings of the individual's subjective illness accounts.

Fear and Abandonment in Bangalore

In this section I will provide ethnographic vignettes from Asha residents who participated in individual interviews and focus groups. The purpose of these excerpts is to demonstrate the various motivations, concerns, and reasons for which these residents voluntarily decided to undergo psychosocial rehabilitation.

R is a 31-year old Tamil man from Chennai who was diagnosed with schizophrenia 15 years ago, and has continuously stayed in psychosocial rehabilitation (PSR) facilities since then. There is a family history of mental illnesses, as his mother was diagnosed with bipolar depression and was a former Asha resident. R comes from an upper-middle class background: his father founded and operates an IT company, where his older brother also works. His twin sister works in a bank. R did not complete secondary schooling but obtained a diploma in hotel management. He speaks English fluently, and is the most proficient English speaker among the residents. R previously stayed in Asha from 2003-4, and his second and current stay started in May 2015. Once discharged from Asha, R plans to apply for jobs in hospitality management due to his educational qualifications and work experience. Eventually, R would like to return to Chennai, but plans to work in Bangalore in the meantime to gain work experience.

The most important sources of motivation behind R's second stay in Asha come from his two main concerns: first, being unable to interact with "regular people"; second, being sent back to D, a PSR centre he previously stayed in. Both sources of dread serve as equally powerful motivation behind his hopes for finding full-time employment upon leaving Asha. Furthermore, both sources have the same underlying cause of R prioritising socialisation above all other activities in

everyday life. When I asked R about his hopes and desires, he responded:

> I want to be with the regular people [in mainstream society] but I am in a condition in which I am so helpless I have to be put in a [PSR] home with economic support. But that's not something I like. I want to be in the outside group. I want to be with the outside people talking like them, eating like them, sleeping like them, doing my job, to be a normal person.

R is aware of his status as a schizophrenia patient, and that his symptoms hinder his efforts to assimilate into mainstream urban India. He doesn't want to merely mimic 'normal' people's activities. He wants to become one of them by undergoing psychosocial rehabilitation so that society would accept him as a friend, colleague and neighbour. R's comments about his love for social interactions align with my observations of him; whenever I located R, he was almost always found talking to other residents, professional and support staff. Otherwise, he would also approach me to talk about a wide range of topics from Hinduism to Chennai's climate. By continuing to stay in Asha or other PSR centres, R feels as if he is 'fated' to a life without social interactions in mainstream society. This serves as an immense source of dread because R is anxious and hopes to get discharged from Asha, but he cannot do so because of his difficulty in controlling schizophrenia symptoms. Therefore, R remains determined to control and manage his symptoms to ensure he will never return to Asha or another PSR centre.

The second source of R's fears and dreads stems from his past experiences staying at D, another Bangalore-based PSR centre. D remains a source of R's fears due to a punishment scheme they use called 'Time Out,' which involves solitary confinement. R recollects one particular 'Time Out' he experienced in D:

> [At D], if you do anything wrong they'll put you in a dark room and lock you. (...) They put you in a dark room and lock you. There will be light but you will be alone in a room with nobody to talk to. They open [your door], give the food, and [leave]. I have twice tried to escape from [D]. Every time they caught me escaping they [locked me in] for one week. It's called "Time Out." For one full week I had to be without talking to anybody, had to be silent.

R adds a warning from his brother about the consequences of misconduct during his stay in Asha:

> [My] brother has warned me that if I get into drug addiction I will go [back to D], which is unlikely. But still he has given me a warning. Even if it doesn't give me positive motivation,

it will totally demotivate me if I'm doing anything wrong.

By depriving R of his main source of joy in life – talking and interacting with fellow human beings – D has been ingrained in R's head as a dreadful PSR facility to which he never wants to return. Although R's accounts will need to be corroborated with recollections from other clients at D, it is a horrifying experience to be physically and socially isolated. To ensure R remains compliant with house activities and focused on rehabilitation efforts, his family has used a potential return to D as a threat. This demonstrates the severity of the psychological pain R received from his stay in D, and he does not want to experience it again. R's return to Asha therefore marks a grave turning point in his life. If he cannot manage his schizophrenia symptoms effectively to re-establish functionality, he will be staying in some PSR centre for the rest of his life. If he tries to rebel and aggravate Asha residents and staff, his family will likely send him back to D, a place with which he associates horrific experiences of total isolation. R's hopes for complete socialisation outside of Asha are thus laden with negative emotions such as dreading a potential return to D, and permanently staying in PSR facilities – pessimistic fatedness.

Flee(t)ing Fate: S Runs Away from Asha

For schizophrenia patients such as S who never completely accept their diagnosis, PSR becomes a seemingly insurmountable task. S is a Bengali woman in her 30s, hailing from New Delhi. She is highly educated and well experienced in professional services, having completed her Master of Business Administration at 23 and worked at banks when she was living in New York City and Philadelphia. She has been diagnosed with schizophrenia and her positive symptoms primarily involve delusions about her family. Since S was the youngest child and the only daughter in the nuclear family, her father met S's every whim. S has two brothers, who are occupied with their own families and the younger brother does not live in India. Additionally, her mother also was diagnosed with a mental illness. This has meant S's family has primarily relied upon PSR service providers to look after her. After having spent several years in different PSR centres, S arrived in Asha with a desire to return to Delhi and regain her autonomy by having a full-time job and living on her own. The role of Delhi in S' interviews and informal discussions was significant: she yearned for North Indian — especially non-vegetarian — dishes, and frequently described her childhood home to me during our informal discussions. Delhi was portrayed by S as her idyllic city, or at least the only Indian city she would consider living in.

S was an active participant in Asha activities, but compliance was not achieved with a complete

understanding and acceptance of her illness. Asha staff informed me that S did not acknowledge her diagnosis of schizophrenia. In the past, she asked several psychiatrists to provide her with a CT scan or proof of chemical imbalances in her brain. Nonetheless, she agreed to take anti-psychotics, see her psychiatrist, and undergo psychosocial rehabilitation. S perhaps thought that she would be able to demonstrate her stable condition to family members by maintaining treatment compliance. Self-awareness of schizophrenia has mixed treatment outcomes that depend on how the individual internalises their diagnosis (Lysaker et al. 2002). For some schizophrenia patients, it can be uplifting and refreshing to finally identify the source of their frustrations and delusions. For others, their exposure to social stigma attached to the term 'schizophrenic' further led them down the path of denial (Lysaker et al. 2007). Based on the aforementioned evidence, S found self-realisation of illness to be more restricting than liberating. PSR for S was not so much about regaining functionality but an opportunity to demonstrate her supposed normalcy, which was being contested by her psychiatrist and family.

Despite her denial of the schizophrenia diagnosis, S's yearning for independent living and return to a career in banking motivated her to be compliant with house activities. S described her stay in Asha as largely enjoyable in her individual interview in spite of its constraints on her autonomy, such as infrequent access to non-vegetarian food. Asha staff and S's family encouraged her to take accounting classes at the local computer school and she enjoyed engaging in household chores such as washing clothes, and interacting with other residents. This was the 'work of hope' in action: Asha staff and S's family recognised her hopes to return to the banking sector, so they provided her an opportunity to take accounting theory and software classes at the local computer school. From the informal conversations we had, S genuinely enjoyed learning about accountancy. I frequently noticed S doing her homework and revising in the afternoon when other residents would be sleeping or playing board games. S wanted to live independently and work in a bank, which motivated her to be compliant with house activities. She believed that if she made satisfactory progress in Asha by adhering to its practices and values, then she would be granted a discharge from her psychiatrist and be able to return to Delhi.

However, S ran away from Asha three days after the first focus group discussion took place. What seemed like a routine trip to the computing class resulted in S taking a train from Bangalore to New Delhi, her hometown. It was assumed the precipitating factor in S' decision to leave was her psychiatric consultation during the weekend, when her psychiatrist informed S that she would not be able to go to Delhi for the foreseeable future. Once S had acquired sufficient funds to purchase a train ticket and maintain self-subsistence, she decided to flee from Asha. S seemed to contemplate her decision until the very last minute: when staff asked whether S wanted to join

the residents in their monthly movie excursion she initially agreed but rescinded her decision, saying that the accounting classes were important to her. She then left Asha as per schedule for her 10am class, but did not return to Asha until 3pm. Staff realised something had gone amiss, contacted administrators at the computer class and found out S was absent. Numerous phone calls were made to S's cellphone but she had switched it off. Asha staff then informed her two brothers about her disappearance. The next day, S's older brother called his mother, who told him that S had arrived in New Delhi and was on her way to the family home.

Since S ran away from Asha, I could not conduct the exit interview or the second focus group discussion with her. Nonetheless, based on the aforementioned ethnographic evidence, I argue that S felt Asha and her family were depriving her of her autonomy, which compelled her to leave Bangalore unauthorised. Once S's psychiatrist informed her that she would not able able to return to Delhi for the foreseeable future, this triggered anxiety and created fears of staying in a psychosocial rehabilitation centre forever. S's recollections of experiences from her adolescence and university student years demonstrated that she values her autonomy immensely. S's sense of pessimistic fatedness — being sent from one PSR centre to another until death — repeating yet again overshadowed her hopes for Asha as a place for planning the future. S's hopes for living independently, which she thought were being actualised by taking accounting courses and partaking in Asha activities, were dashed by her psychiatrist's refusal to grant her permission to leave Bangalore. This resulted in a chain reaction where the psychiatrist's refusal led to S taking radical action: running away from Asha without any of her personal belongings so that she could return to New Delhi.

Repeat Visitor: H's Social Anxiety and Filial Piety

Occasionally, some residents such as H undergo repeat visits to Asha because of their inability to independently manage schizophrenia symptoms. Such decisions are not made lightly, as I will demonstrate by elaborating upon H's circumstances. H is a male in his 30s with a middle-class background from a North East state. His schizophrenia symptoms started from the age of 19 in 2001, and H has experienced them continuously for the past 14 years. H's father operates a Liquid Petroleum Gas (LPG) distribution plant but according to H, he should have retired quite some time ago; his father continues working to financially support H. Like most participants in the pilot study, H completed a Bachelor's degree but was unable to complete a Master's degree. This was due to his social anxiety, which affected his cognitive functioning. I noticed this when I first met H, as he struggled to read more than two lines of text at a time. Once getting discharged,

H hopes to either sit the Civil Services Examination or operate his father's distribution plant so that he could financially support his parents.

H first stayed in Asha during 2013 but left before completing his Trial Stay due to his anger towards staff and residents, stemming from his delusions about other people mocking and gossiping about him. H returned to Asha a second time in June 2015 to attempt rehabilitative treatment once more. When I asked H about what he thought caused his anger to flare up during his first Trial Stay, he responded:

> The medicine [I was taking at the time] had many positive effects... but there was only one negative effect. That I had become little short-tempered. If anyone did anything wrong... I used to get angry. But in other ways... by and large there were positive effects. My confidence level had increased... I had more self-confidence... I felt I was more [independent]. There were many positive effects, but I had become short-tempered.

Additionally, staff had informed me that H's positive symptoms are represented by a delusion about people talking behind his back. Even in his second stay in Asha, H was certain that other residents were mocking him while he was away from their sight. He developed an adage to describe his delusions:

> In any place you go, whether it's in my place or Bangalore, whether it's Asha or NIMHANS [National Institute of Mental Health and Neurosciences] or New York City or Sydney, everywhere, there will be some two or three peoples among [a larger group], there will be some people who won't be that good. Or who will be mean people. So during my stay at last time, two residents and one female resident, so three residents [were in] that category.

A particular incident however compelled H to leave Asha and return home in 2013. All staff and residents of the Richmond Fellowship Society (India)'s Bangalore facilities took part in a Bangalore-wide World Mental Health Day celebration alongside other local PSR service providers. H however refused to attend because of M, a staff member who H thought was in the category of inherently antagonistic people. He did not want to interact with her at all and did not want to attend the event, but grudgingly agreed when the CEO of RFS(I) Bangalore personally asked him. H soon confronted M verbally about leaving Asha:

> I decided I'll go back [home], rang my psychiatrist and I told him that one of the staff is ill-treating me. [Then] he said "You think over it, but I cannot do anything about it." So after

that two to three days went and again I felt that [M] was ill-treating me. So I told M one morning "You want me to go? Fine, I'll go."

Even before the World Mental Health Day celebrations, H suspected M of verbally abusing and mistreating him; H commented that even after stopping the problematic medication, he still thought M was being antagonistic. Eventually, H left Bangalore to return home, and he immediately requested his psychiatrist to stop prescribing him the medication that he thought made him short-tempered:

I requested [my psychiatrist to stop the prescription]... he was not of the opinion to stop this medicine. He said "See, as there are many positive effects, like you are able to comprehend better, and you are feeling more self-confident, self-dependent. (...) Why don't you control your anger? Everyone gets angry." I said "Sir, because of this medicine, I think I'm getting very short-tempered." So in spite of the fact that there were many positive effects to me, so if I was getting short-tempered it was actually not affecting me, but others were getting affected. (...) Within 6-7 days... my temper had come down. And I was again calm like before. But along with that the positive effects had also gone.

H reflected upon his past actions and came back to Asha a second time, being determined to make amends with staff and move on. After returning home and no longer taking the medication H thought made him short-tempered, H tried to gain readmission into Asha after being convinced by his psychiatrist to give rehabilitation a second chance. He had to wait in his hometown from November 2013 until June 2015 because there were no vacancies in Asha. Additionally, staff were apprehensive about H returning due to his previous stay. When H finally returned to Asha, he was looking for a long-time Asha volunteer called Dr J, who helped him during his first Trial Stay in 2013. This was because H thought he had treated her harshly on the day of the World Mental Health festivities, and wanted to apologise to her. When H saw Dr J in the staffroom one day, he apologised to her in person about his demeanour; H said he would have apologised to her even if he spotted her in public. The fact that H was aware of his behaviour, remembered it for several years, and personally apologised to people shows his potential to overcome his symptoms and actualise his hopes. However, his delusions and social anxiety are unlikely to disappear instantly due to his world views being entirely based on said delusions, and H is aware of this. Whether H will change for the better by having greater self-confidence and controlling his delusions remains to be seen.

Finally, financial implications are equally important for H's motivations during his second stay in

Asha because he does not want to financially depend on his father. Asha's monthly fees excluding medication fees and recreational services are 17,000 Rupees (US$251.48), while the Indian Gross Domestic Product (GDP) per capita in 2014 was US$1581.50 (World Bank 2015). The average Indian must therefore pay 15.9% of their average annual earnings once every month in order to send their family member to Asha. While R and S come from financially stable families who are able to unconditionally support them, H does not have similar kinds of safety mechanisms. H considers himself as the cause behind his father's continued involvement in the labour force, and believes his father should have retired. The commotion surrounding H's first Trial Stay in 2013 created a strong sense of regret in him, as seen by the apology he made to Dr J when he returned to Asha in 2015. He is determined to take advantage of his second opportunity, but his delusions about fellow residents and extreme introversion prevent him from doing so. H will need to start trusting fellow residents and staff, and detach himself from the delusions about gossiping if he wants to financially support his father. Time is running out for H to sit the Civil Service Examination due to its age restrictions, while his elderly father continues to operate the family LPG distribution plant. There are many tensions that H must address during his second stay in Asha, in order to accomplish his hopes of filial piety and regaining autonomy.

Conclusion

The journey schizophrenia patients embark upon in search of self and their hopes is laden with fears and hardship. From the vignettes included in this chapter, the common thread that links all of them together is the fragility between hope and fear, and the amount of effort residents and their families have invested in PSR. R has lived in PSR centres for the past 15 years, and yearns to be discharged in order to socialise with 'normal' people. He dreaded his memories from a previous PSR centre where he experienced solitary confinement, and his brother uses this fear to ensure R complies with Asha staff's requests. S was working towards realising her hopes by taking accounting classes as preparation for re-employment. However, a visit to her psychiatrist drastically altered S's opinions and experiences of Asha, and she fled from Bangalore by taking a train. H returned to Asha in June 2015 because he knew his father could not continue to financially support him. H felt he had to start working to support his parents, but his social anxiety and delusions continued to hinder his cognitive abilities and functionality. None of these residents' PSR experiences were easy or pleasant; each one had to confront their fears and learn to overcome them in order to continue their journey of recovery. Despite hopeful individuals' attempts to impose some kind of structure onto the future – something that is inherently uncertain – they are at the mercy of external circumstances. In the next chapter, I will discuss and critique

how the PSR literature's definition of meaningful work as full-time, waged labour is problematic. By restricting the concept of work merely as a means for economic autonomy and subsistence, PSR service providers ignore the myriad ways in which people define the kinds of activities that are meaningful in their lives.

Chapter 3: Redefining 'Meaningful Work' for PSR Service Users

Generally speaking, gaining and staying in employment is portrayed as the ultimate challenge and object of desire in psychosocial rehabilitation. In particular, the low employment rate of schizophrenia patients, and their high willingness to get employed serve as motivation to undergo vocational activities (Bond 2004). Estroff (1995:89) however criticises the PSR literature's predominant interpretation of 'work' as full-time, waged labour by highlighting different kinds of activities persons with mental illnesses undertake outside of the market economy. It is important to consider that subsistence is not always the primary motivation for PSR service users engaged in job searches. For example, service users could value tasks such as household chores and volunteering just as much as full-time waged labour. Although almost all Asha residents expressed interest in joining the labour market once they were discharged, certain residents' motivations suggest that if they could find something else to do besides work to fulfil their hopes, they would do so. Personal growth and interests should be taken into account when devising an employment plan for clients, as the objective of PSR is to guide people to overcome their mental illnesses and live the life they want. In this chapter I present three ways in which Asha residents view 'meaningful work': 1) 'work' for economic and social autonomy; 2) 'work' as an avenue for socialisation and integration into society; 3) 'work' for providing opportunities for personal growth. I argue that PSR literature overly focuses on conceptualising 'work' as full-time waged labour, when it should adopt a person-centred approach instead to incorporate the various ways in which individuals define 'meaningful work.'

Vocational Training in Psychosocial Rehabilitation

Vocational training and job placement are two major activities in the PSR recovery process, due to its goal-orientation focus and the ubiquity of 'work' (full-time waged labour) in mainstream society. PSR's behaviourist approach is best exemplified by its vocationally minded activities: work provides opportunities for persons with severe, persistent mental illnesses to exercise cognitive abilities such as exercising personal discretion, making decisions, and completing mutually agreed upon goals and tasks (Bennett 1970; Bond 2004). As a result, PSR activities focus on teaching social etiquette, effective verbal communication and body language and provide opportunities for clients to practise them across different social settings. Clients are expected to learn and familiarise themselves with these social skills through repetition and receiving

constructive criticism from staff and fellow clients (Kopelowicz et al. 2006; Liberman and Silbert 2005). To supplement group therapy activities, American PSR providers introduced supported employment schemes to teach vital job search skills such as preparing a Curriculum Vitae and answering interview questions (Becker and Drake 2003). When these schemes incorporated teaching modules for skills commonly used in workplaces such as stress management and social etiquette, participants in said scheme received more employment offers in competitive industries than the non-participants (Wallace and Tauber 2004). Through the training of practical skills, persons with mental illnesses can gradually re-assimilate themselves into the larger community as they start to think, act and socialise in line with fellow community members.

In countries such as India, subsistence dominates PSR service users' opinions of work because there is a dearth of disability support schemes. Due to their lack of participation in the labour force, American schizophrenia patients' economic needs often exceed their contributions to society. It follows that many people with schizophrenia are dependent on the welfare system for subsistence, such as receiving disabled support income (Estroff 1993). In contrast, Murali and Rao (2004) reported that many Indian caregivers of mentally ill persons in PSR facilities valued full-time wage labour the most, because the family members wanted clients to be capable of looking after themselves and to earn an income. Such perspectives are influenced by the fact that disability income support and other welfare measures in India are virtually non-existent. This is because the ambiguous wording in the Persons with Disabilities Act (1995) frames disability welfare schemes as a 'charitable act,' when it should be considered instead as a citizenship right for persons with disabilities. Consequently, central and state governments have done little to implement any substantial support systems (Coleridge 1993; Karkal and Shihabuddeen 2014:250). Since family caregivers cannot look after their mentally ill relatives forever, pragmatism therefore largely dominates Indian PSR service users' thoughts concerning 'meaningful work.'

However, we fail to consider two important points when we narrowly 'work' only as full-time waged labour: 1) the diverse ways in which schizophrenia patients are already contributing to society; 2) the need to guide persons with mental illnesses towards functionality and independent living in a holistic manner. By defining 'work' as full-time waged labour, schizophrenia patients' ability to subsist independently in the informal economy is overlooked. Although participation in the market economy through formal channels such as employment is not the only means of demonstrating productivity, schizophrenia patients' lack of involvement with said channels entrenches the stereotype of these patients as unproductive members in American society (Estroff 1993, 1995). However, the Indian informal economy was estimated to involve 150 million people

in 2009-10, and this was considered an underestimation (ILO 2012). Panhandling, self-employment as street food vendor, embroiderer, tailor and other tasks is a common feature of the Indian economy, to the extent where clients who attend embroidery and printmaking classes in Chetana receive orders from local factories and stores to make bags. Additionally, Estroff (1995:86) argues that PSR's fixation on gaining full-time employment as a key treatment outcome de-emphasises 'the experiential, sensate, emotional core' of people, stating that rehabilitative activities have become overly fixated with developing 'external' skills concerning socialisation. While the social and cognitive benefits from work have been noted in Bennett (1970), Becker and Drake (2003), and Bond (2004), PSR clients should not be forced into employment. Instead, they should be given opportunities to pursue careers in their areas of interest and at a pace that suits their needs.

A person-centred approach towards devising an employment plan is therefore necessary in a PSR setting, and Asha does this with all residents. When taking a new resident's case history, Asha staff ask the resident and their family about future aspirations and preferred career paths. Instead of assuming that all new residents will want to engage in full-time waged positions, Asha staff listen to residents and their families prior to formulating a course of action. From the information gathered from residents and their families, staff have a better understanding of each resident's educational, cultural and family background. This will help them identify and incentivise various vocational and psychotherapeutic activities for each resident to ensure the 'work of hope' begins in earnest. Asha staff therefore endeavour to accommodate individual-specific aspirations and goals as much as possible, as they recognise that everyone has different hopes and dreams. For example, P hopes to study soil science and agriculture at university in order to travel around India and advise farmers on growing sustainable crops. He additionally enjoys swimming, and asked Asha staff for permission to visit the local pool twice a week. Although Asha staff did not allow P to swim due to house requirements on supervising residents undertaking sports or physical activities, a staff member helped P register for his Indian School Certificate examinations and find private tutors in the neighbourhood. By getting to know each resident's personality and interests, Asha staff are able to create routines and emplot rehabilitative activities to ensure the 'work of hope' is operational for all residents.

The Urban Indian Cultural Life Course: Individuality vs. Conformity?

The urban Indian cultural life course — a chronological set of expectations that cultural groups inscribe upon certain age groups (Loustaunau and Sobo 1997) — is hard to define due to the

tension between people's private and social lives, and deciding whether to prioritise parental expectations or personal aspirations. The joint family model has remained as the default model of social organisation in all of India, irrespective of ethnicity, religion or regional background. Generally speaking, male children live with their parents even after they start their own families. Once married, female children will leave their parents' homes to live with their husband's family (Tyler 1973:129-130). Many upper-caste, middle-class Hindu male adults remain dependent upon parental or other authority figures to make decisions on their behalf. This is because filial piety makes these Hindu males happy, knowing that they were able to reciprocate the kinds of love and affection their parents had provided (Derné 2005, 2009). More specifically, social pressure guided Hindu males in their everyday life, and they openly accepted its prevalence in their lives (Hastings 2002). For example, Derné's (1992:263) interviewees stated that they did not want to 'dishonour' their parents by pursuing individual desires. This statement aligns with Kakar's (1981:121; cited in Derné 1992:264) observation of Indian society as a place where 'to conform is to be admired; to strike out on one's own, to deviate, is to invite scorn or pity.' Indians who are eager to please their parents will have their life courses largely contoured by parental expectations, which can vary depending on each family's socio-economic circumstances.

Contrary to what Derné (1992) observed in North India, Mines (1981, 1988) reported that urban Indians, both male and female, started to prioritise their personal desires over social expectations from their late 30s to early 40s in Tamil Nadu. Mines (1981:101) observed the following pattern in his respondents' life courses, which were quite similar to the American life course: ages 17 to 24 represented entry into adulthood, 27 to 33 was a transitional, reflective period for people to consider their actions as young adults and work towards their life goals, and 37 to 45 entailed a transition into seniority, confronting death and feeling a sense of fulfilment in one's personal and professional life. These periods of transition were followed by periods of stabilisation that typically lasted six to eight years (Mines 1981:101). The first transitional period marked uncertainty, as people attempted to mediate tension between personal and parental career expectations, and sought advice from elders (Mines 1981:104, 1988:572). The second transitional period entailed a mixture of marriage, employment and parenthood, and the kinds of combinations chosen depended on the individual's decision to either adhere to parental expectations or to deviate from them (Mines 1981:106, 1988:573-4). The third period involved people pursuing personal interests in-depth, now that they had largely fulfilled their obligations to their children; a growing sense of repressed desires started to appear among respondents (Mines 1988:572). The schism between personal desires and family expectations started at a relatively early point in the South Indian life course, and continued to grow if people decided they want to value their own aspirations.

Again, a person-centred approach is the ideal method to take in this instance due to its emphasis on clients' subjective experiences, and their cultural influences. Both Mines (1981, 1988) and Derné (1992) commented that their interviewees were more willing to share their private desires and thoughts during the interviews than in informal conversations. Since family members, neighbours or passers-by in the community were not present, the participants felt they were liberated from social pressure and therefore they could express more personal ideas. A similar effect was reproduced during the second focus group discussion, where participants wanted to exclusively talk about how Asha staff could provide them with adequate career guidance. Discussions were mostly centred around participants' past work experiences, their family's and personal expectations for employment and devising possible courses of action to undertake while in Asha. While the participants were aware of social expectations surrounding employment based on their age, some of them did not want to conform to said expectations. Participants then proceeded to discuss what they wanted to tell Asha staff about improving their employment prospects, be it as a volunteer or a full-time position. By understanding the client's upbringing and social environment and how these factors influence their thoughts, PSR service providers are better positioned to understand their clients' needs and expectations and provide relevant activities.

Work for Economic and Social Autonomy

Here I present S and K as case studies that mostly conform, albeit with some subtle differences, to the urban Indian cultural life course I described in the previous section. As briefly discussed in Chapter 2, the main recurring keyword in S's self-narratives was 'independence.' S highly valued her autonomy, and this served as a major source of motivation during her stay in Asha. The following is an excerpt from her pre-focus group interview:

> So when I was like 22, I was staying in a hostel out of... Delhi... and doing my MBA. Since the age of 22 only I've been independent, and before that from my birth, my father used to encourage me to play various games like badminton, so I have friends. (...) I was quite independent, but my father used to do everything for me, whatever I demanded from him. I like independence actually. I don't want to be dependent on somebody. So if [Asha staff] allowed me to go the doctor's on my own, I can go on my own for consultation. Otherwise, it's not convenient for my brother to come down to take me to the doctor.

S's emphasis on living as a single female since the age of 22 — a young age for Indians, especially women, to be living outside of their family homes (Mines 1988) — and comments about playing sports and pursuing a Master's degree in her early 20s demonstrates her love for independent living. S is the youngest child in her family, and her father spoiled her; S could rely upon her father to have her needs met. In spite of this, S wanted to independently undertake tasks meaningful to her, such as pursuing studies, interacting with friends and playing sports. It is possible that her parents were overprotective, which strengthened S's desire to reduce their involvement in her life. This is however a hypothetical statement, as I was unable to gather further information to verify this claim. What is certain is her preference for autonomy, and being able to identify and satisfy her desires independently with no interference from external entities such as Asha staff.

In order to work towards achieving her aspirations, S took accounting theory and software classes at the local computing school. Asha staff informed me that S's brothers wanted S to undertake some kind of vocational training during her stay in Asha so that she would be able to re-enter the labour force after getting discharged. After asking S and her brothers about possible career paths, everyone agreed that S working as an accountant in a bank would be idea. This was due to her previous work experience as a financial advisor in the banking sector in the United States, and family history – S's father and both of her brothers are accountants. Asha has previously sent several residents to a computing school in the neighbourhood that teaches web design, basic programming and word processing software skills. Staff suggested to S's family about sending her to this school to learn how to use accounting software, and both S and her family agreed. Once she started taking accounting classes, this activity became emplotted into S's rehabilitative journey as an imaginary place where she can aspire towards independent living, and actualise said aspirations by undertaking practical tasks (Mattingly 1994). For S and her family, economic and social independence is of utmost importance. This was noted several times during her interview with repeated mentions of wanting autonomy and complete freedom of choice in her life.

Similarly, K wishes to be discharged at the earliest in order to enter the labour market and pursue a career in software engineering. He is a Hindu male in his mid-30s from Bangalore who completed a Bachelor's degree in mechanical engineering, and arrived in Asha during 2013. Interestingly, K's delusions and hallucinations encourage him, and are not antagonistic. He was often seen walking around the Asha courtyard smiling and talking to himself. When I asked him about this, he told me that he was talking to a little girl in the park. Asha staff have previously told me that when they asked K who he was talking to, his responses varied from a local engineering recruiter, an owner of a small manufacturing company to kind strangers on the street. When I

asked K about what he wants most from Asha during both individual interviews, his reply was blunt and relevant, albeit founded on unrealistic assumptions. The following excerpt comes from K's first individual interview, when we were discussing K's post-discharge plans and how he intended to enact upon them:

BL (Interviewer): What would you like to do once you get discharged?

K (Interviewee): I'll look for a job.

BL: Ah, job search. Do you think Asha can help you in your job search?

K: Yeah they're giving me feedback, which I can take to the employer.

BL: What else do you think Asha can do to help you find a job that you like? Is there something you wish the staff would do?

K: I told you - I want them to give me good feedback.

The two individual interviews I conducted with K followed a similar path as the excerpt. He provided monosyllabic responses, repeated comments about finding a job and pointed out his lack of work experience. Although he did not have an elaborate plan like S to enter the labour force, his desire for employment and independent living was clear from the interviews and focus group discussions. From observing K throughout fieldwork, I noticed that he struggled to stay awake during the day, despite not being insomniac. Despite attending Chetana workshops and actively participating in house activities, K remained unenthusiastic and sleepy because they were unrelated to his ideal career path as an engineer. In contrast, when focus group participants were sharing their work experiences and feedback they wanted to provide to Asha staff, K was eager, focused and shared his opinions on other participants' suggestions. I do not know whether K's desire for employment and getting discharged is a part of his schizophrenia symptoms. The judgement was difficult to make because K was functional enough to provide coherent responses during the focus groups and interviews, albeit often monosyllabic ones. Nonetheless, H made explicit his desire for employment and getting discharged so that he could live independently.

Work as an Avenue for Socialisation and Assimilation into Society

While S and K's motives for finding a job — economic self-sufficiency and social autonomy — are generally understood as the most common reasons behind PSR clients' wishes to seek work (Bond 2004; Murali and Rao 2004), they are not the only reasons. As stated in Chapter 2, R's desire for employment stems from his hopes for social assimilation:

> I've only done three jobs properly - one is in data entry, one is in housekeeping in hotel, and another in room service in another hotel. And even in these [jobs]... I got such bad feedback, but... those were the best times of my life. Whenever I worked, whenever I had people around me, joking, discussing, playing pranks and doing their job seriously and having a good time with my peers, and seniors, that was the happiest moment of my life.

For R, work is not a means for subsistence, but rather for socialisation and interacting with 'normal' people. When asked about the importance of 'independence' in his life, R replied:

> I don't need to be independent. My brother is ready to support me lifelong. And whatever I earn is for myself, he has told. And my father has enough money - if he [buys] me a house in my name I can run with that money lifelong. But he's not ready to do it because I haven't proved myself. (...) So my brother has said that as long as you're in Asha, or you're at some [PSR facility] in India, I'm ready to support you lifelong, how much it costs, I'm ready. You don't have to work but anything you do, do it well, earn money, enjoy it with yourself.

R interpreted the word 'independence' to be economic independence, and claims that he does not need it due to unconditional financial support from his family. For R, employment is also a means to an end, but a different one to K and S — socialisation and assimilation into mainstream urban India. He still wants to undertake waged labour in order to maximise opportunities for social interactions but will consider other avenues if necessary. While most persons with schizrenia will emphasise income as a key criterion in their job search, any job will suffice for R, provided it has adequate opportunities for social interactions. People's subjective experiences and thoughts matter because they can, and often do, have different ideals surrounding work and other categories of social activity (Estroff 1995). Even if R acquires a job where he earns insufficient income to subsist, he will continue doing said job if it provides him with sufficient opportunities to develop friendships and camaraderie with colleagues. R does not need to work but wants to do so anyway, although for reasons one would not have valued as highly. For R,

employment's merit as social capital is greater than its 'concrete' by-products such as wages. Put succinctly, he wants to be employed because he wants to be with 'normal' people in their typical environments.

Religion forms a core part of Indians' identity and community, and R was no exception to this rule. From the most recent census conducted in 2011, only 0.1% of the respondents stated 'no religion' as their response (Census of India 2011). R is a follower of the International Society for Krishna Consciousness (ISKCON), commonly known as 'Hare Krishna,' and visits an ISKCON temple every weekend to give prayers and socialise with fellow devotees. When I asked about the role ISKCON plays in his life, R replied:

> If I did not join ISKCON I either would have been dead or been caught for murder, or murdered in a way, or I would have committed suicide. (...) I had to find a job after my first exit in Asha... [but] I could not do anything. I was in such bad shape. (...) I would have been involved in so many negative activities because my mind is so abstract in thinking. One thing that still keeps me alive is ISKCON. That's my greatest pleasure in my life. Even working is not up there. Another thing which happened after joining ISKCON is getting a close group of friends who love and share so many things with you. We talk to each other freely, and [fellow devotees] don't interfere in my personal matters. They don't ask questions like "Where do you earn? How much do you earn? What is the nature of your job?"

ISKCON is a greater source of joy than employment in R's life, because the pleasure he receives from socialising with fellow devotees exceeds the happiness he feels while working. Psychiatric studies that report positive outcomes from the role religion and spirituality plays in PSR processes argue that such belief systems serve as coping mechanisms, instill self-confidence and an optimistic outlook for the future (Longo and Peterson 2002; Mohr and Huguelet 2004; Mohr et al. 2006). R too has experienced this through ISKCON, because it serves as a non-judgemental, inclusive and supportive place for him that even employment cannot offer. Whereas R's work colleagues could ostracise and stigmatise him due to his status as a schizophrenia patient, ISKCON devotees are forbidden from talking about such personal matters. For R, a job is a means to an end, but not material subsistence, because he prioritises his social life above all other activities and desires.

Work for Personal Growth: Volunteering and Community Betterment

In this section, I present excerpts from G's interviews as a case study to illustrate another possible definition of 'work' for PSR service users: volunteering for skill maintenance and altruism. G is a 67 year-old Tamil woman from a rural background. She has three tertiary qualifications — Bachelor's degrees in Information Science, Law and English Literature — and has worked as a secretary and a librarian. Considering her social status as a retiree and her old age, G is more interested in the personal development and altruistic aspects of 'work.' When I asked her about the kind of 'work' she wanted to undertake, she responded:

> I want to use my knowledge... if [staff] tell me to do something, I will do [it]. I've [studied] English literature, law, and library science. If [staff] can give me something to do regarding these 3 subjects I will be happy to do anything. So if they give me something to do at the Chetana library... if they make me sit down and do some literature work... to do some counselling or read some book and translate, I'll be very happy.

Since G's son has informed her that he will be able to financially support her while in Asha, G's definition of 'work' is centred around personal growth. Additionally, G said that she particularly enjoyed taking computer classes in Chetana because she was learning something completely different. G was familiar with printmaking and embroidery — the other two classes offered at Chetana — but she had never owned a computer. G therefore prioritises personal growth and development over economic activities because she enjoys the experience of developing new skills while retaining existing ones, and does not need to work to financially support herself.

Furthermore, G is happy and satisfied with her life when she is able to meet expectations from her status as the elder 'statesperson' of Asha by providing guidance to fellow residents:

> So many people have so many problems with life. So when [other residents] come to me with a problem I try as much as possible to comfort them. All of them like me, and I like all of them. Everyone comes to me with a problem and they ask me for advice. (...) When they come to me I try to tell them what is good and what is not good and I try to pull them out from their concerns.

Despite G's age, she wants to continue working because she enjoys helping other people, and continuing to hone her skills while learning new ones. Due to her extensive educational

background and employment history, G feels like she is capable of making positive contributions not only within Asha, but also in the local neighbourhood where Asha is located. According to the PSR literature's definition of 'work,' G would not be deemed unproductive and lazy because she is contributing to her surroundings by helping those in need. However, she would not be considered completely 'productive' either because she is not undertaking a full-time, paid position (Estroff 1993, 1995). Most importantly, her contributions as ad hoc counsellor and advisor to Asha residents should not be dismissed. I observed that residents frequently approached G to seek advice on interpersonal relationships, interpretation of religious scriptures and personal issues such as managing emotions and overcoming social anxiety. H commented in his second interview that talking to G was greatly beneficial to him because of her encouragements and advice concerning his anxieties and introversion. Again, Estroff's (1995) case for incorporating the 'interior' qualities of a person such as emotional wellbeing, and a sense of personal growth into PSR activities demonstrates its importance with G's desire for volunteering. She is not interested in working for earning a wage but to engage in two activities that she finds meaningful: opportunities to continue using her skills and helping other people.

Conclusion

This chapter demonstrated, and argued for, the need for PSR practitioners to broaden their definition of 'work' beyond full-time, waged labour. Values from the urban Indian life course are embedded in Asha residents' self-narratives about their ideal futures, and in house activities. The emphasis on employment and work is one such example. Generally speaking, relatives of urban Indian mental health service users want their kin members to be prepared to commence employment when they are discharged. This is because family members could die unexpectedly soon and residents would need to be financially independent. However, enforcing the aforementioned definition of work onto residents without understanding their family backgrounds and past experiences is problematic because we end up ignoring the ways in which residents themselves define productivity and meaningful activities. The sociocentric ways of select members in Indian society means that people will not always consider income as the primary criterion in their job searches, as illustrated by the financial and moral support R and G receive from their kin. Other forms of labour such as volunteering are equally valuable and productive usages of labour and should be understood as such. By taking a person-centred approach, we discover the myriad ways in which people define 'meaningful work.' To this end, Asha staff respect and value residents' opinions and life experiences by asking questions about their plans for the future while taking case histories, which will help staff design and emplot appropriate

rehabilitative activities for each resident. The next chapter discusses how the work of hope involves a collective effort in its maintenance, and critiques the overly individualistic conceptualisation of hope by demonstrating how ecological relationships help create and nurture hope within Asha residents.

Chapter 4: Rethinking Hope in Ecological Terms

This thesis thus far has argued for a rethinking of hope's role and processes in the PSR literature, due to its hitherto myopic depiction of the work undertaken to cultivate and sustain hopefulness among PSR service users. During fieldwork, I realised that there exists a networked system of emotional labour — a sort of 'ecology of hope' — that was mutually created and sustained among the residents, the institution, and the residents' families. This network served to collectively nurture hope and a positive outlook for the future within the residents, despite the bleak psychiatric prognoses faced by schizophrenia patients. Being aware of how volatile and damaging a relapse is for schizophrenia patients' sense of self, Asha staff and the residents' families collaborate to provide a support system for patients. Hope is therefore not an emotion exclusive to the individual, but rather, an attitude generated through distributed social labour and emotion work involving a number of people (Hochschild 1983). The interdependence between residents and their social surroundings is vital in maintaining each resident's hopes throughout the recovery process. I argue that this independence can be expressed in ecological terms: each resident influences their social and physical surroundings, and vice versa (Folke 2006). Ethnographic vignettes from observations, focus group proceedings and individual interviews will be provided to illustrate how hope as an emotion works best when it is collectively and ecologically developed between Asha residents, staff and the residents' families.

The Overly Individualistic Depiction of Hope in PSR

Hopes cannot be accomplished by the hopeful individual on their own, due to their externally contingent nature. While the act of hoping generally starts from an individual, the realisation of hopes is dependent on external entities such as chance, fate and other people's actions (Crapanzano 2003). For example, persons with schizophrenia could hope for a complete cure, but this depends on researchers identifying and developing a suitable solution. Hoping on its own is insufficient; not only must people work towards realising their hopes by undergoing relevant activities, they will additionally need to hope 'for the best.' To this end, Asha staff engage in emotional labour in order to incentivise house activities and engender optimism among residents. Emotional labour is social regulation conducted by workplace authorities in order to enforce a certain set of visible and bodily representations of select emotions among its employees, such as politeness, warmth and friendliness (Hochschild 1979, 1983). In a PSR setting, service providers are advised to maintain a positive outlook towards recovery to their clients even when

circumstances suggest otherwise. Although Asha residents are encouraged to express themselves in group therapy sessions, they are asked to share concerns surrounding death and other sensitive issues privately to staff in case a resident might find the topic distressing. Staff undertake emotional labour to forcibly engender optimism within Asha (even among acute schizophrenia patients) to ensure everyone is treated equally, and to maintain cheeriness among residents.

Additionally, a socially distributed effort to create and sustain hope involves interdependent, ecological relationships maintained by hopeful individuals and their social surroundings, such as family members and PSR staff. Desroche (1979:16-19) presents hope as a state of 'collective ideation,' where adherents of a certain belief system collectively work to concretise their abstractions and imagined beliefs. A synergy effect is often felt in such communities because members feel they can accomplish together what they cannot do alone due to the confidence they gain from being surrounded by like-minded people. While Anthony (1993, 2000) and Liberman and Kopelowicz (2005) emphasise the relational aspects of PSR recovery, they do not sufficiently explain how other people (such as family and friends) in a client's life can bring about positive change. This is where an ecological approach can shed light on how a PSR client's social surroundings influences their rehabilitative progress. For example, Asha residents rely on staff for guidance, to transfer practical knowledge and provide psychotherapy when necessary (all Asha staff are qualified psychiatric social workers or psychiatric rehabilitation professionals). Conversely, staff depend on residents' opinions for house activities, as well as information on their aspirations and desires so that they can plan individualised rehabilitative schemes. Both staff and residents rely upon each other to collectively work towards converting residents' hopes into practical tasks that residents can undertake. Provided the residents successfully complete these activities and external circumstances such as chance are in their favour, their hopes are then actualised in everyday life.

Through a collective effort to create a synergy that cultivates hope among hopeful individuals and their social surroundings, resilience is expected to be developed over time. Resilience is typically defined as 'the ability to rebound from adversity and prevail over the circumstances in our lives' (Marsh et al. 1996:4), but this is an incomplete definition. Folke (2006) argues that resilient people in a socially ecological system should be able to grow and expand their capacities from overcoming disruptions. By withstanding different situations of adversity, members of the ecological network learn from the experience and will be better prepared when similar disruptions take place in the future. This is the kind of resilience that PSR should be instilling in its service users: as discussed in Chapter 1, schizophrenia patients cannot ignore the possibility of relapsing and losing their functionality and sense of self. Resilience helps residents deal with

unexpected, adverse situations in their lives because they will have developed a sense of calmness and confidence, and be equipped with a wide range of skills to tackle their problems (Liberman and Kopelowicz 2005; Liberman and Silbert 2005; Ong et al. 2006). To ensure residents do not become recidivists in PSR facilities (although this is always difficult due to the possibility of relapses), staff must instil the kind of resilience that encourages personal development and growth within residents.

'Working' Towards Hope

In line with previous chapters, I will present interview excerpts and observations of Asha residents to illustrate the various ways in which hope is collectively nurtured between residents, their families and Asha staff.

One of the factors behind R's resilience and optimism for the future is the work Asha staff conduct by creating activities for R to work towards accomplishing his aspirations, a progression he can follow in order to actualise his hopes. For example, Asha staff approached R about teaching public speaking in English to Chetana clients twice a week for one month, as a trial employment programme. At the end of each session, Chetana staff assess R's performance and provide him feedback. If R received positive comments throughout the entire trial period, Asha staff would consider recommending to his psychiatrist that he be allowed to seek part-time employment. R enjoyed teaching the Chetana clients:

> I've [almost] completed my 4 week course in Chetana... after which [Asha staff] has said I can start applying for a job in Bangalore. 3 weeks is over, I only have one week remaining and after the fourth week I'll be [looking for] a job. Even if [Asha and Chetana staff] find discrepancies in my [performance during the final] week, I'm willing to wait and once I get a job I'm willing to give my 100%. So the changes are very much there (...) [Asha staff] gave me an option [to conduct the classes]... I wanted to do it, so I accepted.

Asha and Chetana staff collaborated to find an activity that provided possibilities for R to realise his hopes of seeking employment opportunities at the earliest. Asha staff were aware of his loquacious personality, and thought R would enjoy and succeed at teaching public speaking in English to Chetana clients. R realised that if he could demonstrate to Asha staff that he is able to stay focused during his four-week trial, then they will perceive this as progress in R's recovery process. Asha staff have materialised R's hope of re-entering the workforce by providing an

opportunity to demonstrate his competencies. As a result, the externally contingent aspect of hopes (Crapanzano 2003) is assuaged by the presence of an activity and clearly established possible outcomes. R either performs up to a satisfactory level and receives support from Asha staff to look for a job, or he is criticised by both Asha and Chetana staff. R believes he is in charge of his employment prospects, because *he* is able to control his performance in the public speaking lessons. R is therefore hopeful that his performance in the speaking classes is sufficient to elicit positive feedback from Asha and Chetana staff, leading to opportunities to seek employment and potentially get discharged from Asha.

Examples such as R's Chetana classes demonstrate the emotional labour Asha staff undertake in order to maintain optimism and resilience for residents to continue undergoing PSR activities. Since a halfway home is by definition a transitional place, Asha staff identify the kinds of activities residents can imagine themselves doing in the future and provide relevant tasks to 'work' towards doing said activities. Even if the residents struggle to complete general house activities or tasks they were specifically assigned to do, they nonetheless feel as if they are making progress towards actualise their hopes (Campling 2001; Kennard 2004). R stated that even if Asha and Chetana staff are dissatisfied with his overall performance in the public speaking class, he is willing to wait until they grant him permission to seek employment opportunities. The opportunity to teach English made R feel like he was undertaking meaningful tasks to actualise his hopes, and provided a brief but meaningful impression of social expectations in workplace environments. R's self-confidence and patience increased from the combination of his family's unconditional support for him and Asha staff's tailored tasks, and he feels more calm and confident about successfully completing his rehabilitative journey. By making all residents feel like they are working towards their hopes while undergoing their tailored activities, Asha staff are able to maintain residents' optimism for the future.

Therapeutic Purgatory: Importance of Family Involvement

In order for the 'work of hope' to operate effectively, all members in the ecological network must be involved in the resident's life, including their family members. The importance of resident-family ties in Asha was noted through K's experiences of PSR, as he ended up in a state of what I call 'therapeutic purgatory.' K's brother is the designated local guardian[5] whose interest in K's rehabilitative progress declined over time. Initially, K's brother was punctual to all meetings and

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[5] A resident's local guardian is responsible for taking them to their psychiatric consultations, and are encouraged by staff to visit Asha occasionally.

psychiatric consultations that K had to attend, and called him at least once a week. However, K's father became ill, and the brother was now asked to manage both K and their father. With subsequent psychiatric consultations the brother would either not arrive on time or ask to re-schedule the day before. He also requested to delay payments for K's stay because the family could not financially support both K and his father. When the brother had agreed to visit Asha during mid-October K was informed of the visit and became visibly happy, even wearing a formal dress shirt to impress him. Again, K's brother asked to postpone the visit by calling Asha at 3pm, despite K having waited the entire day to see him. What was initially a collaborative journey had become an isolating one for K, who remains in a state of rehabilitative purgatory: functional enough to be yearning constantly for a discharge, but left neglected by his family.

The importance of family caregivers in the recovery process has been thoroughly documented in the PSR literature, and its importance is perhaps greater in Indian contexts. Marsh et al. (1996:6-8) note the importance of family involvement in the recovery process for clients in the U.S.: almost 88% of the caregivers who participated in the study commented experienced positive outcomes, such as increased cohesion from working together to solve problems, and feeling gratified about their work as advocates and caregivers. Similarly, countries with collectivist societies were reported to have better treatment outcomes than their individualist counterparts in the International Pilot Study of Schizophrenia. Its results have remained intact in follow-up studies, and the joint family kinship model was stated as a possible factor for India's comparatively high recovery rates (Leff et al. 1992; Stanhope 2002; WHO 1973). Although the joint family model is no longer as prevalent in urban areas due to increasing female labour participation, parental expectations and other forms of 'social pressure' still provide comfort and stability in people's lives (Derné 1992, 2005; Kapur 2000). In contrast to R who remains hopeful knowing that his family unconditionally supports him morally and financially, K is uncertain about his family's involvement because they are mostly concerned with his father's health. His brother requesting Asha staff to delay payments demonstrates that the family's focus is completely on the patriarch's wellbeing, and K has been consequently ignored. Without family support, K is stranded. Asha staff have tried to force K's family to engage with him and provided relevant activities for K, but he remains unattended and uncertain about his hopes coming to fruition.

Focus Group Discussions: Opportunities for Holistic Growth

The residents-only focus group discussions intended to provide a space for residents to express their opinions without any external pressures, and for all residents to work collectively to achieve their respective hopes and aspirations together. During the last month of fieldwork, I organised two focus group discussions. I noticed that the residents were not taught how to negotiate in Asha, and wanted to see if they could teach each other how to do so in a group discussion setting. If successful, this would suggest that residents could conduct social skills training independently, which in itself would improve their interpersonal skills. The first one involved compiling general feedback from participants' experiences of Asha. The second focus group had a specific topic that arose from the first focus group, which was: "What can Asha do to provide career advice to residents?" Participants specifically wanted to discuss what Asha staff could do in order to help them re-acclimatise themselves into the urban Indian labour market, and suggested initiatives such as designating 'Job Search' as a monthly workshop theme. Mock job interviews were another suggestion that was generated from the discussions, suggesting that all the participants were focused on finding a career path that is relevant to their interests and studies. The focus groups were intended to serve as a non-judgemental space in which participants could freely share their opinions with one another, generate ideas collectively and negotiate with Asha staff on the kinds of changes they wished to create.

With help from supportive participants, H experienced holistic growth when his self-confidence increased from facilitating the second focus group discussion. H's world views are founded on a 'big/little person' binary: the former category represents extroverted and confident people, while the latter category represents the opposite. H considered himself as a little person who was frequently exploited by antagonistic big people, although not all big people were malignant. During the second focus group discussion, G was initially the facilitator but was unable to stimulate discussion. Some of the participants had forgotten how the group discussions worked, while others had completely erased it from their thoughts. H intervened and explained the focus group procedures patiently to the other residents and started asking questions to participants to encourage them to speak. If someone tried to interject, H replied with "Please let me finish what I have to say first, then you can tell me what you think," something that a 'little' person would be incapable of saying. Eventually H took over as the primary facilitator for the focus group, and the participants were able to address a wide range of issues concerning full-time employment. Although H acknowledged that the absence of an antagonistic big person (in his case, R) in the

second focus group positively affected his willingness to participate, the opportunity to interact with fellow residents provided H a chance to challenge his self-image.

Furthermore, H had never done any mediation or facilitate group discussion before. This was not surprising because of the tension Indians face between deferring to parental expectations or pursuing their self-interests (Mines 1981, 1988). I however could not rule out the possibility that H had learned negotiation skills beforehand and asked:

> BL (Interviewer): Have you tried mediation?
>
> H: Never Ben, never. This is the first time. No, never.
>
> BL: Do you know mediation?
>
> H: Yeah to express it to others and make them understand.
>
> BL: And to resolve conflict, solve any conflict between two different people. (I then provided a brief example from an incident between H and P, who was another focus group participant)
>
> H: Okay, that is mediation. I did not know.

I showed H an excerpt from the second focus group, where he was facilitating discussion. H initially refused to acknowledge that he was being a 'big' person while watching video footage of himself taking command and ensuring participants remained on-topic:

> But I personally think that [the focus group format] is nothing difficult to understand. It was very simple, that is why I understood [how it works]. If it was a little difficult I would not have understood. So the concept and the project and... guidelines of the project were simple enough. (...) I give credit to [the project's simplicity].

H had experienced an egodystonic moment: his actions in the second focus group as a 'big' person clashed with his self-image of being 'little.' He initially did not want to acknowledge the changes he experienced, and deferred to the simplicity of the focus group procedures. However, his facial expressions during the post-focus group individual interview suggested that he was happy about being informed about how he managed to overcome his social anxiety and low self-image. Due to his lack of self-confidence, H relied on discussion group participants to provide a supportive environment in which he felt comfortable to exchange ideas and share experiences. Similarly, the participants were dependent on a resident to take charge of facilitation discussions because G could not do so. H took the initiative on his own due to feeling confident enough to

take charge, and was able to actualise his hopes for being more confident and extroverted by being a leader.

When asked about his thoughts on the focus group discussions, H replied:

> I did not know that this kind of thing exists, to be very honest. So now that I know, at least here, I am 100% sure that it will work for the betterment of the residents. (...) I think it's a very good project and personally I would like to continue in the future such group discussions. There are some many residents who have... positive feedback on this, and they are also interested to continue.

H's egodystonic experience during the second focus group discussion shows how his hope for overcoming social anxiety was realised collectively by H and his fellow residents, even if it was only for two hours. H did not know beforehand how to mediate and facilitate discussion within a group because his social anxiety had hitherto prevented him. When presented with a supportive environment involving fellow residents from a similar background, H responded by assuming leadership of the focus group without me or another participant intervening. Other residents provided H with self-confidence to use his leadership skills and work towards his hope for overcoming social anxiety. If H hopes to be confident enough with social interaction to successfully manage his father's LPG distribution plant, then he needs to work on his self-confidence and public speaking skills. As I showed in Chapter 2, H came back to Asha a second time to overcome his social anxiety issues and become more confident in verbally articulating his opinions — both orally and in written form. Through the focus group discussion, H was able to temporarily brush aside his social anxiety and took advantage of the opportunity to demonstrate his leadership and public speaking capacities. All the participants benefited in the end as H worked towards overcoming his anxiety issues and experience a new kind of self, while other participants found the discussions to be informative and interesting.

Focus Group Discussions: Learning from Experience

In this section I use KR's experiences of the second focus group as a case study to illustrate how residents can help each other achieve their career goals by sharing their past work experiences and providing suggestions on each resident's career plans. KR is another resident who enjoyed the second focus group discussion due to its focus on the job search process and being able to share her work experiences. KR is a female resident from Bangalore in her 30s, who finished a

Bachelor's degree and is looking for her 'perfect job,' which she defined as one that suits her interests and areas of expertise. She has previous work experience as a call centre worker and secretary but found those two jobs difficult, due to stigma from her colleagues and inability to concentrate on her tasks. KR nonetheless was certain that she wants to re-enter the labour force:

> I like to work more. I like to continue work. Depends upon our capacity, where we will work in the job. I need to see that the whether we have to go for the job or we are fit for the job or not. So we have to say, we have to know, take the discussion, what we have to do.

KR particularly enjoyed the second focus group discussion due to its topic – career guidance. Like S, KR wanted to be re-employed at the earliest, and thought the focus group was a useful hub for exchanging information with fellow residents:

> It was very good... we were about to tell everything of what our experiences, work experiences. (...) We had discussed a lot about work experience. And [the more we know about each other's work experiences, it will help us]. We had to tell lots about our work experiences and past in detail, and what we did. But it was very nice. This is a part of community. So, if we are in a group — even I noticed — we will get something from them and individual is good, but sometimes if we want to talk to some person, we can have a chance for that (in a group), only for some purpose. But other things, if we sit in the group, if we are discussing in the group, then we'll get more information from them.

KR is saying that the more participants share their work experiences with one another, everyone benefits by gaining additional knowledge about various industries, and they can use the information to visualise and create their ideal future employment plans. KR points out the collaborative nature of the 'work of hope': by sitting and discussing together as a community, everyone gains new information from each other. In the discussion group, KR shared her experiences of working as a secretary and call centre worker. Additionally, she listened to G talk about her time as a librarian and a secretary, discussed the kinds of social stigma the two of them faced, and provided advice on responding to interview questions. Through this act of sharing knowledge and lived experiences, KR is able to work towards her hopes by gathering additional information on the labour force, while helping other residents with their own career aspirations. Asha residents are creating interdependent, ecological relationships among themselves, through which they can help one another with their respective aspirations.

Conclusion

Although a person's hopes stem from their own desires, the 'work of hope' involves, and depends on, their social and physical environments. This chapter demonstrated how hope as an emotion in PSR is created ecologically between PSR staff, service users and their families. I illustrated that the work of hope is most effective when all parties collaborate with one another, by providing excerpts from the focus group discussions and Asha staff creating tasks that were relevant to residents' aspirations. R would not have had the chance to prove his organisational skills and professionalism if Asha and Chetana staff did not provide him with an opportunity to teach public speaking. H would not have experienced a positive form of egodystonia if he didn't feel comfortable to assume leadership among the focus group participants. KR showed that residents can help each other with their career aspirations by sharing information and past experience, from which each resident can vicariously learn about the labour market. Additionally, all three residents had supportive families who were involved in their kin member's rehabilitative progress. In contrast, when not all members of a resident's social surroundings are involved in the rehabilitative process, their aspirations could not be realised, as seen in K's case study. The 'work of hope' is therefore optimised when ecological relationships exist between residents and their social surroundings to create a supportive network, where residents can undergo something they would not be able to do alone – actualising their hopes.

Concluding Remarks

In this thesis I have presented a critique of the overly monotonic inflection of hope and work in the psychosocial rehabilitation (PSR) literature, highlighting three thematic areas that need to be more fully developed in order to understand the role of hope in the rehabilitative process for schizophrenia patients.

As I have demonstrated throughout this thesis, a person-centred ethnographic approach is well-equipped to tap into individual-level motivations, desires and concerns, thereby acting as a corrective for PSR's culturally biased approach towards rehabilitating people with severe mental illnesses. In order for hopes to be articulated verbally and by activities (the 'work of hope'), schizophrenia patients need a sense of self that is functional and coherent enough to identify their aspirations and desires. In Chapter 1, I stressed the importance of providing mild to moderate schizophrenia patients with opportunities to construct self-narratives. This helped schizophrenia patients to not only refine and articulate their own aspirations and potentialities, but to create a socially legible self that the larger community recognises. I then demonstrated (throughout Chapters 2, 3, and 4) how Asha patients were able to articulate and enact upon their hopes and aspirations with help from staff and residents' respective families. It is important to note that the residents' aspirations and conceptualisations of keywords such as 'meaningful work' did not always conform to the PSR literature's findings, and Asha staff accommodated and respected each resident's subjective definitions. In doing so, PSR clients are able to undertake the 'work of hope' to concretise their own aspirations through undertaking tailored and/or house maintenance duties. These activities not only teach practical skills, but also attend to residents' self-confidence and emotional stability. Although the journey towards independent living is paved with tension between optimism for the future and pessimism for relapsing or hopes not coming to fruition, Asha residents nonetheless continue to work towards their hopes by relying on an ecological network supported by their families and staff.

The first deficit in the PSR literature is its overly positive, homogenous depiction of hope as a determinant in the recovery process. As demonstrated in Chapter 2, the 'work of hope' is laden with negative emotions such as fear, dread and pessimistic fatedness that served as points of tension for Asha residents. The stakes of PSR are high for residents such as H, who came back to Asha a second time in order to eliminate his social anxiety, and prepare for employment to support his father. Independence remained a key tenet in S's life and she was willing to do whatever it took to re-establish it, to the extent that she ran away from Asha. Even for someone

such as R whose family provides unconditional moral and financial support to stay in a PSR facility, his experience of staying in another PSR centre haunts him. None of these residents said that their experiences of PSR have been simple or easy: H was concerned about his reputation among Asha residents; S and R were afraid of 'fate,' concerned that their pasts would simply repeat (resulting in permanent residence in PSR facilities until their deaths); R especially dreaded social isolation. If recovery is understood as an incremental learning journey of trials and tribulations (Anthony 1993; Deegan 1988), then the cultivation of hope should also be understood as such: a process fuelled by the tension between optimistic and pessimistic emotions, akin to tightrope walking.

The second weakness in the PSR literature is its myopic definition of 'meaningful work' as full-time waged labour, and the refusal to consider alternative interpretations of the term. As Estroff (1995) pointed out, PSR has several problematic assumptions derived from Anglo-Saxon cultural values: individualism, fixation on waged labour, and exclusively focusing on a person's 'external' features of selfhood. The combination of these three values has created a distorted lens through which 'work' is understood, as anything other than full-time, waged labour is de-emphasised. Subsistence is not always the main agenda for PSR clients wishing to re-enter the labour force: as seen in Chapter 3, R's desire for employment stems from his yearning for socialisation and assimilation into mainstream society. His family is able to support him financially, but he nonetheless wants to continue working in some capacity because socialising is a fundamental source of his happiness. Similarly, G wishes to 'work' as a volunteer to hone her areas of expertise; she immensely enjoys helping fellow residents and wants to retain her skills while doing so. For every typical motive such as economic and social independence, there are many other valid reasons why Asha residents want to 'work.' Therefore, the definition of 'work' in PSR should be broadened to incorporate and accurately convey the client's desires. There are other equally relevant forms of compensation besides wages, such as a sense of purpose and fulfilment.

Finally, the third area of concern I identified is the overly individualistic interpretation of hope that has hitherto largely dominated the PSR literature. Although Anthony (1993, 2000) has emphasised the relational aspects of hope in the recovery process, others such as Russinova (1999) and Deegan (1988) have primarily interpreted hope as an individualistic emotion. In response, Chapter 4 presented hope as an ecological process involving PSR clients and their social surroundings: fellow residents, facility staff and the residents' families work collaboratively to guide each resident in their pursuit for certainty amidst an uncertain future. Although hopes and aspirations are often personal and stem from an individual, the realisation of said hopes are contingent on external entities such as chance and other people's actions (Crapanzaro 2003). The

'work of hope' transforms not only the hopeful resident but also their families, and Asha staff. Furthermore, it is one thing to remain stable amidst shocks, but an entirely different matter to continue growing and developing as a person from said shocks. I therefore argued that resilience must also be emphasised as a key element in the 'work of hope.' The burden of cultivating hope is distributed across this support system, so that PSR clients learn how to rely upon others when necessary and gradually develop a sense of resilience.

Hope often plays a pivotal role in helping persons with schizophrenia maintain optimism for the future, and comply with treatment programs. Additionally, hope helps guide patients in their efforts to understand the impact of schizophrenia in their lives, and to devise a process — therapeutic, developmental, vocational, to name three possibilities — through which they regain their dignity and capacities to better understand their illness experiences (Deegan 1988; Schiff 2004). Indeed, similar usages of narratives for re-establishing a direction and purpose for people with other terminal and/or chronic illnesses (such as cancer and infertility) have been documented extensively (Becker 1997; Good et al. 1990; Mattingly 2010). However, the way hope is portrayed in the PSR literature does not provide a complete picture of how it is operationalised by service providers and users. The monotone, overly positive inflection of hope is problematic because it fails to capture the fragility and delicateness of schizophrenia patients' hopes (and provides little room for understanding the specific dreads and fears that accompany the work of hoping for this population). The potential of relapsing never quite goes away for most persons with schizophrenia: people cannot be 'cured' from schizophrenia, but are taught how to manage its symptoms instead (Anthony 1993). This places schizophrenia patients in a constant state of existential uncertainty, one that is arguably more acute than the kinds of instability faced by people in everyday life. Hope as it has been understood in the PSR literature fails to take this into account, and the goal of this thesis has been to broaden our understanding of both the potential and pitfalls of hope in the PSR setting.

Based on the preliminary results of this project, further research into the role of narrative in the treatment of schizophrenia should be undertaken to test the results' validity over a longer time period. Roe and Davidson (2005) have argued for the importance of emphasising individual agency during the recovery process for mild to moderate schizophrenia patients by providing them opportunities to create and share their illness narratives. Considering that schizophrenia is self-defining illness (wherein the disease category engulfs the sick individual's identity), the psychiatric literature on schizophrenia has largely portrayed patients as 'self-less' persons, lacking self-awareness and personal identity (Estroff 1989, 1993). This thesis however demonstrated that most Asha residents were capable of narrating their desired path towards recovery, incorporating

both past illness experiences and future projects into their developing self-narratives. Since I was only in Asha for three months, sustained evaluation could not be conducted; I do not know how stable these self-presentations are over time, nor how effective they prove for moving these people toward their desired futures. A qualitative longitudinal study involving participant observation and interviews could help shed light on the causes behind schizophrenia patients' presumed (in)ability to create self-narratives. That said, during the time I was there, Asha residents were able to orient themselves—relatively coherently and consistently—toward their desired futures, and self-narratives were a key tool they used to actualize their hopes for these futures. This has significant treatment implications, because PSR staff will be able to engage in therapeutic emplotment to incentivise treatment, potentially leading to a more fulfilling and rewarding recovery experience.

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Appendix A: Ethics Clearance Letter

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MACQUARIE
University
SYDNEY·AUSTRALIA

14 May 2015

Dr Aaron Denham
Department of Anthropology
Faculty of Arts
Macquarie University
NSW 2109

Dear Dr Aaron

Reference No: 5201500065

Title: *Politicising Mental Health: Participatory Development and Mental Health Services in Chennai, India*

Thank you for submitting the above application for ethical and scientific review. Your application was considered by the Macquarie University Human Research Ethics Committee (HREC (Human Sciences & Humanities)) at its meeting on 27 February 2015 at which further information was requested to be reviewed by the Human Research Ethics Sub-Committee.

The requested information was received with correspondence on 15 April 2015 and 13 May 2015.

The HREC Sub-Committee considered your responses out of Session.

I am pleased to advise that ethical and scientific approval has been granted for this project to be conducted at:

- Macquarie University

This research meets the requirements set out in the *National Statement on Ethical Conduct in Human Research* (2007 – Updated March 2014) (the *National Statement*).

This letter constitutes ethical and scientific approval only.

Standard Conditions of Approval:

1. Continuing compliance with the requirements of the *National Statement,* which is available at the following website:

http://www.nhmrc.gov.au/book/national-statement-ethical-conduct-human-research

2. This approval is valid for five (5) years, subject to the submission of annual reports. Please submit your reports on the anniversary of the approval for this protocol.

3. All adverse events, including events which might affect the continued ethical and scientific acceptability of the project, must be reported to the HREC within 72 hours.

4. Proposed changes to the protocol must be submitted to the Committee for approval before implementation.

It is the responsibility of the Chief investigator to retain a copy of all documentation related to this project and to forward a copy of this approval letter to all personnel listed on the project.

Should you have any queries regarding your project, please contact the Ethics Secretariat on 9850 4194 or by email ethics.secretariat@mq.edu.au

The HREC (Human Sciences and Humanities) Terms of Reference and Standard Operating Procedures are available from the Research Office website at:

http://www.research.mq.edu.au/for/researchers/how_to_obtain_ethics_approval/human_research_ethics

The HREC (Human Sciences and Humanities) wishes you every success in your research.

Yours sincerely

[signature]

Dr Karolyn White
Director, Research Ethics & Integrity,
Chair, Human Research Ethics Committee (Human Sciences and Humanities)

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research* (2007) and the *CPMP/ICH Note for Guidance on Good Clinical Practice*.

cc. Mr Ben Lee

Details of this approval are as follows:

Approval Date: 14 May 2015

The following documentation has been reviewed and approved by the HREC (Human Sciences & Humanities):

Documents reviewed	Version no.	Date
Macquarie University Ethics Application Form	2.3	July 2013
Correspondence from Mr Ben Lee responding to the issues raised by the HREC (Human Sciences and Humanities)		Received 15/4/2015 & 13/05/2015
Participant Information Statement – Observational Studies/Ethnography/Anthropology	1	30/3/2015
Participant Information Statement entitled *Politicising Mental Health*	1	30/3/2015
MQ Participant Information and Consent Form (PICF) entitled *Politicising Mental Health: Participatory Development and Mental Health Services in Bangalore, India*	2	15/04/2015
Semi-Structured Interview Questions	1	4/2/2015