Manual 4

Rehabilitation of Persons with Psychosis

What we know so far from our research and experience

Key research findings

In this age of computer searches and free open access to so much academic material, there is a risk of turning a blind eye to personal research experience. This manual, as part of PHF Fellowship project resources covers research completed by our own research pool, researchers working with IPH and those who completed Doctoral work under our guidance.

We also briefly touch upon research work from India as well as the world over, in terms of good practices in working with cognitive, emotional and social aspects through the rehabilitation process. In order to make the research findings reader and user friendly, we have attempted to weave together the data and conclusions from our scientific work, with the practical, day-to-day practices at Tridal which are built upon these conclusions and pointers.

When an institution chooses a focus of work and intervention, it is also important to share with interested partners, what was learned over the years, in the course of research of persons who are part and parcel of that institution. The Institute for Psychological Health has the rather unique privilege of having within the fabric of the team, people who focused on Schizophrenia rehabilitation in the course of their Doctoral research.

Dr. Shubha Thatte worked on the research topic of Attention in Schizophrenia in the 1980s, when in fact curiosity on the subject was just getting kindled the world over. Her first Doctoral student, Dr. Anuradha Sovani once again chose to focus on clinical dimensions of symptomatology of schizophrenia, Positive, Negative and Mixed symptoms, which were just catching the interest of the psychiatric and psychological world in the mid 1980s, and completed her work in 1990, examining what kind of interventions work best.

Dr. Sovani's Doctoral student Dr. Savita Apte, an integral part of IPH, focused on group interventions for Caregivers of Schizophrenia, which were clearly answering a felt need in the 1990s. Her work explored burden, burnout and stigma experienced by family members who were caring for the affected person.

In the interim, in the latter half of the 1990s decade, Dr. Thatte and Dr. Sovani worked on a UGC funded Major research project focusing on what works with treatment resistant conditions. Research partners Dr. Deshpande and Prof. Kinkar, and Dr.s Thatte and Sovani worked with persons living with chronic psychotic conditions for a considerable period of time, and in whose case unfortunately, the condition showed relapses in spite of use of appropriate pharmacological intervention. Some of the key findings from this work will be presented here, although there is a publication based on this Major Research project (listed at the end of Manual 1)

In the years that followed, three of Dr. Sovani's Doctoral students chose to pursue various dimensions of this fascinating condition, throwing light on neuropsychological underpinnings, clinical-neuropsychological correlates, and caregiver misconceptions. Dr. Shweta Kadaba, Dr. Sunitha Shankar, and Dr. Priyanka Jagtap respectively have permitted the manual writers to share a summary of their work, although it has also been published elsewhere. They have also kindly agreed to serve as external partners in the process of manual completion, auditing of the material documented and validation and field testing of the manuals, since all three are in active psychological practice in Mumbai and Bangalore, in hospital as well as clinic settings. Their remarks and suggestions are appended towards the end of this manual.

What readers will find in the pages that follow, are brief outlines of conclusions drawn from the research work of all the people described above. Immediately following each piece will be a text box or a subsection with examples from Tridal of how those findings were translated into practice at Tridal, or experiences of our Tridal team that reflect these learnings.

Savita Apte:

Most of the Caregiver training manual which is a part of this set of material, is a reflection of Savita's work, both Doctoral and that done thereafter. However, it would be interesting to review her key findings documented as early as 2004, two decades before this material is being compiled.

An interesting aspect of her study design was that it was longitudinal, with assessments of stigma, burden and burnout deciding which need based intervention package the caregivers would receive first, depending on their predominant requirement. Another assessment followed this targeted intervention, after which all 70 caregivers participating in the study received the further aspects of the package addressing their secondary requirements, to ensure ethical completion of delivery of all trainings to all participants since ultimately all received all inputs and training was not withheld from anybody in this pre-post, own control design.

The caregivers whose highest felt need was stigma management, were mainly female, and predominantly parents of patients. They benefitted very significantly from the targeted intervention, but did not show much further improvement in stigma reduction with the full package intervention.

Those with highest felt need for burden management were an equal number of males and females, either parents or spouses of patients. This group was the smallest in number, and showed no significant shifts in burden reduction either with targeted or full package intervention although there was some relief and reduction in burden scores.

Those whose highest felt need was burnout management were the largest subgroup. Many experienced burnout even if they were living apart from the patient they were helping to manage. The number of males in this group were approximately twice as many as the number of females, and all relationships were represented, including parent, spouse, and siblings. This group was helped with both, the targeted intervention for burnout, s well as the full package intervention.

Coping skills of all caregivers were also assessed, and it was seen that there was a marked increase in positive coping and decrease in negative coping among all caregivers from pre- to post-intervention. The high stigma group showed a large rise in positive coping, and the high burden and high burnout groups showed a marked decrease in negative coping strategies.

It is important to review what was used as a specific intervention package for each of the above problem areas. Psychoeducation was seen as the means to counter stigma, since stigma usually arises from lack of knowledge, and holding on to myths and misconceptions about a condition. In Savita's research, psychoeducation was used with caregivers, but as a fallout of our work, IPH began many stigma reduction programs for the community as a whole, and also for those with lived experience of psychosis.

Problem solving training was used as an intervention for burden. Caregivers needed to address specific burden areas such as financial burden, burden of time devoted to care, and so on, using time management skillfully and addressing the problem at hand without the emotional baggage.

Finally, caregivers were trained in emotional regulation to handle burnout. Cognitive intervention trainings were included in the package, specifically REBT oriented inputs which would help them unpack the way they were perceiving their own life situation.

Shweta Kadaba:

Shweta earned her Doctoral degree in 2005.

The work is relevant even today due to the emphasis on visual and verbal processing, and exploration of two apparently distinct groups, patients with psychosis and with brain disorders, a comparison that makes more sense today with our understanding of neuropsychology. She later worked much more extensively in the neuropsychology domain, acquiring PG Diploma level training in applied neuropsychology from Bristol University, UK, as recently as 2021.

In her study design itself, she drew interesting parallels and contrasts between a neuropsychological disorder like Temporal Lobe Epilepsy and a functional disorder like schizophrenia or psychosis, in times when it was still looked upon as a functional disorder, also incorporating a matched control group with similar educational and socio economic status. But what was more memorable about the work to me, was that she proposed the possibility of rehabilitative and cognitive remediational interventions for multiple groups to be conducted together, even though they were poles apart in their pathophysiology (eg, electrophysiological v/s neurochemical) given the sheer paucity of professionals and trained volunteers available to carry out such work.

Rather than delve into her study findings, this manual will help highlight the suggestions she made based on her research, which may prove useful to support groups and activity centers that with to draw upon the resources created for such cognitive and social remediation and intervention as part of this PHF funded project.

In the comparison between a healthy comparison group and persons with psychosis,she reports that attention to visual and verbal material is poorer in the diagnosed group($p<0.005$), especially sustained and divided attention $p< 0.001$) but the rate of learning remains the same irrespective of modality, unlike in the epilepsy group. Executive functioning is affected as expected ($p<0.01$) as is response inhibition ($p< 0.001$) (the latter in both groups)but simple working memory in persons with psychosis is surprisingly intact. There were in fact, no significant differences between the persons with psychosis and the healthy controls.

Memory capacity and information processing capacity is decidedly lower ($p<0.005$), mainly since mnemonics are hard to use due to poor encoding. However, once learning did take place, it was consolidated into long term memory as evidenced by delayed recall; and in any case, as expected cuing aided recall.

Semantic ($p<0.001$) and phonemic ($p<0.01$) fluency was affected. In contrast, for the Temporal Lobe Epilepsy group, visual attention and visual working memory was impaired ($p< 0.005$) but verbal/auditory attention was intact (comparison with healthy control yielded non significant results.). For this group, working memory was intact but verbal fluency was poor. Locus of the lesion did not affect performance much, except for the expected effect of left hemisphere lesions on verbal recall.

The implications for rehabilitation for both groups thus were as follows:

- Modules need to be short and simple.
- Distracting material or different kinds of learning should not be attempted at a single time point.
- Material should be organized with clear cues and memory aids like chunking
- Repetition is very useful, but only small amounts of material can be given at a particular point. The learning curve will not increase beyond a point
- Motor speed should not be assumed since some slowing will impede performance
- Cuing at retrieval offers advantages.

What is more interesting is the suggestions offered while merging groups for rehabilitative work. One group can serve as a peer support to the other in their area of strength. Eg. The patients with Temporal Lobe Epilepsy have more intact auditory memory than visual and barring the consolidation process, they can help persons with psychosis. Their attentional

capacities are also better, but once material is well learned there is no difference between the groups.

On the other hand, persons with psychosis can consolidate, and benefit from encoding and retrieval cues and could handhold their TLE counterparts in these domains. Rate of learning is slower for persons with psychosis, but forgetting is higher in persons with epilepsy, and both groups are susceptible to interference effects. These findings offer a blueprint for ways in which interventions could be combined for both, and also how they could support and assist one another. Some interesting qualitative observations recorded by Shweta include the fact that members of a support group of persons recovering from schizophrenia and other psychoses were very insightful about performance of other group members, They could successfully predict which members would perform well among the members who were being tested, showing good understanding of the cognitive processes of people they were familiar with. They were also able to judge if they themselves were likely to do better than others, reflecting good metacognition.

She concluded that if we work together on both groups, use both visual and auditory modalities, plenty of repetition, limit information shared in one session, use visual aids and mnemonics to ensure coding, and modules should be short with plenty of breaks.

Do not intersperse too much new material on a single day, and offer feedback after each learning session with some memory enhancing tips. Rehearsal at the end of the day would be fruitful

Concluding this section with a quote from her thesis:

“There was one interaction between a member of an epilepsy support group, and members of the schizophrenia support group, where the former was to demonstrate a skill to the latter. The group was surprised that there existed other people with illnesses other than schizophrenia, who were leading similar lives. The idea of a similar self help group was met with empathy and immediate identification.” She opines that this positive interaction means that getting together people with different illness conditions for purposes of training might add value by increasing their social networks. It would also help psychologically when it comes to acceptance of their condition, with the understanding that “mine is not the only illness that impacts a person’s life.”

Sunitha Shankar:

Submitted her Doctoral work in 2009, but many of the ideas have me to fruition in Tridal.

To quote an interesting excerpt from Sunitha's thesis Rationale, where she draws upon Fisher's work (1999, 2003) "Under the medical model in which mental illnesses are viewed as brain diseases, complete recovery is not a possibility. However, research has shown that many who are labelled as severely mentally ill **do** recover over time, especially when involved with programs that emphasize on hope, optimism and potential."

In her doctoral work, Sunitha found that among the person centered variables explored by her, self efficacy seemed to impact disability associated with work. Invoking Bandura's work on self efficacy, Sunitha emphasized that while working with persons affected by psychosis, their belief concerning self efficacy can be developed by four main forms of influence.

One of these is ensuring that they have **mastery experiences**. Such experiences provide authentic evidence that one can do what it takes to succeed. Another pathway to self efficacy is through **vicarious experience**, in other words, seeing people similar to themselves succeed through sustained effort. **Social persuasion** is a third way to strengthen self efficacy. When persons with psychosis are persuaded verbally that they are capable of mastering a given activity, they are more likely to mobilize efforts and sustain them.

Interestingly, the fourth pathway to self efficacy seems to be through **physiological and emotional states**. These are useful pointers to gauge one's capability. Stress reactions and tension are interpreted as signs of vulnerability. In contrast, positive mood enhances perceptions of self efficacy.

Sunitha cited Liberman's (19) work which hypothesized that self efficacy determines coping efforts and psychosocial functioning. Cognitive and social deficits that arise as a result of chronic psychosis can undermine self efficacy of persons who have suffered from these conditions, and we need to look at these pointers to reinstate their belief in themselves. The pathway to instill these protective factors seems to be through providing mastery experiences, vicarious experiences, social persuasion and positive physiological and emotional states.

The other important person centered variable invoked by Sunitha was social support, which was also an important finding in the UGC funded major research project completed by Thatte, Sovani, Deshpande et al. Social support is seen by theorists to provide a stress buffer. There is also an alternative, direct effect hypothesis which posits that even when persons with

mental illness are stress free, it is beneficial to them to since it creates in them a sense of being accepted, which in turn leads to better interpersonal skills and a positive view of others.

A final person centered variable explored by Sunitha was a relatively unusual one; it also connected more closely with clinical or neuropsychological underpinning of psychotic conditions. This was **belief in the power of voices**, or auditory verbal hallucinations, a variable studied extensively by Chadwick and Birchwood. Almost 75% of persons with psychosis report this symptom and perceive these voices to be omnipotent and omniscient. As Sunitha has correctly concluded in her work, *'coping' with the voice seems to be a more helpful solution rather than 'curing' the voice.*Disengaging optimally with the voices seems to be the most fruitful strategy and interesting research work the world over seems to show that it is not culture bound.

The interesting premise of Sunitha's work, also echoed in a paper presented by Dr. Sovani at IConS, was that although cognitive deficits seem to be at the core of clinical and functional outcomes, their impact can often be tempered by person centered variables. Hence her work aimed to establish whether, although there is ample research that impairment in short term memory, vigilance and executive functioning are associated with poor outcome in psychosis, affecting community outcomes, daily activities, social skills and learning capacity, perhaps bolstering of person centered variables may mitigate their impact. Dr. Sovani'spresented paper had also highlighted the rather confusing finding that independently carried out neurocognitive evaluations of persons recovering from psychosis, and caregiver and volunteer evaluations of their functioning in the activity center, did not necessarily correlate.

This finding which sustains across different data sets and investigations creates hope in the process of Rehabilitation of persons with psychosis. It helps assert that one need not be bound by the degree of neuropsychological damage the disease process has caused; it is still possible to effect sustainable change and re-establish a fairly good level of functioning and independent living.

An important element of any Rehabilitation effort is teaching Coping. In her work she points out that any coping module planned as part of rehabilitation package must not only consider personality factors but look at cognitive capacity of the patients. This may increase the likelihood of the skills taught to them being generalized to different situations and used when required. Coping styles need not categorized as healthy or unhealthy but in terms of their utility to every individual. For example, her research results showed that Beliefs about Voices

significantly predicted Global Disability ($p<0.02$) and Disability related to work ($p<0.04$) Significant associations were also found between Global Disability and Global Functioning and Positive and Negative symptoms.

Work related Disability was found to have a significant inverse association with Self Efficacy ($p<0.008$), Working memory and Logical memory ($p<0.047$). Disability in Communication and Understanding had a significant inverse relationship ($p<0.04$)with Perceived Social Support.

Another important contribution of Sunitha's work was the underscoring of individual variables such as personality factors in the overall case by case prognosis. She emphasized the need to tailor intervention strategies to the patient's stage of recovery, which would encompass an understanding of both, symptomatology as well as cognitive status, as well as to the individual needs of the patient as per their personality make up. As she writes, "treating a disorder is different from treating a patient with the disorder."

Although containing positive and negative symptoms with the effective use of pharmacotherapy is a given, more work needs to be done over and above that. Training in cognitive skills is just as important as raising levels of self efficacy.

Development of social skills would translate to better adjustment, thus indirectly helping to raise self esteem and self belief. To quote from her thesis: "with a sense of empowerment, the person will be able to feel much safer, secure and capable when facing a capricious and seemingly uncontrollable disorder."

Priyanka Jagtap

Submitted her work in 2018, by which time the key issues centered around Caregivers of persons with chronic psychosis, and the myths and misconceptions that hinder good work progress in the community mental health domain. This is interesting since Savita's work with caregivers, a large part of which is reflected in Tridal and in the Caregivers' training manual, was done 14 years earlier in 2004, and explored the key intervention needs of caregivers of persons suffering from chronic psychosis. Is the following findigs will show, there has been much change in the interim, and caregivers already have a more rational understanding of their patients' condition, and know what they require in terms of support and rehabilitation.

Priyanka chose to work with two kinds of caregivers, professionally trained, and those who were family members and volunteers in the support work proffered to persons with psychosis. The family caregivers comprised parents of persons with schizophrenia (40%), spouses (26%), siblings (26%) and children of persons with schizophrenia (8 %).

60% of the professional caregivers were psychiatric nurses and 40% were attendants working with persons with schizophrenia in long stay hospital settings.

Her findings yielded some important insights. Not surprisingly, the professional caregivers understood the symptom severity of persons with schizophrenia better than family members looking after them ($p<0.001$). They also comprehended the possible biological, psychological and social causes at the root of the condition ($p<0.0001$) in contrast to family members who were also more inclined to seek religious remedies at least at first ($p<0.001$).

Interestingly, there was no significant difference between professional and family caregivers in the context of superstitious beliefs like black magic and possession by evil spirits being a possible cause for the condition, and also in choice of routes such as employment or marriage to "cure" it. These findings point to how deep rooted these beliefs are in our culture, and to the urgency for awareness programs for all, including professional caregivers.

There were also no significant differences in the manner in which family and professional caregivers identify experiences seen as problematic for persons with schizophrenia. They could recognize symptoms with equal accuracy. They also perceived the cyclical nature of the illness with equivalent accuracy, as also the perception of control over the illness and attribution of blame. In fact, while neither professional nor family caregivers attributed blame to the patient for the illness, the family caregivers were prone to feel that relatives have more control over managing the disorder than the patient, and tended to attribute blame to themselves if the patient was not managed well.

Professional caregivers, although they understood the condition well, acknowledged that they may have a less coherent understanding of the illness and all aspects of the functioning of the patient, and may exhibit a more neutral emotional response towards the mental health problems of persons with schizophrenia, since they do not share a psychosocial environment with persons with the illness, as do the family members. Professional caregivers however, were more adept at recognizing the condition to be a chronic one, requiring long term management, something the family members did not completely realize.

In terms of rehabilitation needs, the family members expressed a strong felt need for modification of psychosocial attitudes in the community, and more help for families with ill members, as well as skill training. Qualitative exploration of interactions with the family members yielded themes of a high need for psychosocial intervention for persons with psychosis, support for families and creating social awareness and acceptance in the society. As Priyanka wrote, “if caregivers hold misconceptions about what works, the entire rehabilitation program could become ineffective in spite of best efforts towards treatment and rehabilitation.”

What After Us?

The Institute for Psychological Health conducted a large conclave which was titled “What After Us?” in May 2018. This is an issue that hangs over the head of all caregivers of persons with mental illness like a Damocles’ sword. This conclave addressed issues ranging from residences for persons recovering from Mental Illness to financial management of trust funds. The former gave rise to the IPH project *Maitraghar*. This concept drew upon the possibility of several persons recovering from psychosis living under one roof, with custodial care conducted by professionals, and remote monitoring by their loved ones and families. The latter brought under the scanner the issue of insurance and bank schemes for persons with mental illness and their families, and led to much healthy discussion and networking with various like minded NGOs all over India.

The manual was circulated for discussion and suggestions among IPH team.

Three experts, all with a PhD in the area of Schizophrenia and with current work experience in clinical and neuropsychological work with persons with mental illness, were asked to review all the manuals. Their suggestions were incorporated.

Feedback from the independent manual review

Dr. Shweta Kadaba

Consultant neuropsychologist and rehabilitation specialist, Sakra Hospital, Bengaluru.

"It's amazing to see the evolution of Tridal over the years. I was there when it started and it has turned into something so wonderful !!
Big congratulations to the whole team at IPH !!!"

She also made some suggestions in the script of the Manuals which were accommodated in the write up.

Here are the comments for the Activity resource book:
These will be discussed with Fellowship centres in the course of discussions, as each centre may have different experiences.

Feedback on Activities

- **Speed of Processing** –
  Is there training for this to ensure that they can notice errors?
  Would the raising of hand distract the participant? Easier to note errors at the end?
  The idea is to do it as fast as possible but giving the instruction to not make errors may divert their focus ?
  Could train them first on simple version of only one concept – time them and then on two maybe ?

- **Attention – Task 1** – Is it done continuously for 10 mins or in two parts? Is a break allowed? List of numbers may be provided to keep it constant and have the difficulty level maintained to keep the ratio of single vs double digits the same

Instruction – Goal of task to identify number 5 in any language. The goal wasn't very obvious from the instructions. Can be clarified for all the attention tasks.
This is also focused attention. Time between each number should be constant to keep it standard. Based on level of group it may be fixed as every 3 seconds less or more

Task 2 and Task 3 – seems difficult for volunteer to keep track of all participants and errors made while reading out numbers.
Usual formats for divided attention would include two modalities like an auditory and tactile task simultaneously.

Level 6 is a selective attention task as you have to select the number in English only

- **Verbal Learning and Verbal Working Memory**

The task on naming from categories is a **semantic fluency task** – does not involve working memory unless the instruction is that they cannot repeat a name said by anyone before them. The making words from a larger word is a language task and cognitive flexibility/ abstraction. Not verbal learning or working memory – Only done in English so may be limiting in terms of usage.

Verbal learning would involve presenting new information and seeing if they learn over trials or if information is provided and they have to recall immediately and after staged delays.

Verbal Working memory could be a task like – Sitting in circle and each one says a word. The person next to them remembers the word and adds a new one – that is an N Back 1 format task. Other tasks like counting backwards, serial subtractions or days of the week backward are all working memory tasks. Mental math too.
A more complex version is when you recall the word said prior to their adjacent member and adding a new word to it. For eg- 1.Cat 2. Dog 3. **Cat** Lion 4. **Dog** Elephant 5. **Lion** Pig … you have to remember the word given by the person before the one immediately before you. It follows the NBACK 2 procedure.

- **Vocabulary task** does not have problem solving as usually defined. Could be said to have an element of cognitive flexibility/ inhibition as you have to inhibit a response which doesn't fit the parameter.

  Vocabulary , Logical reasoning and working memory level 2 – Requires knowledge of words- semantic memory and response inhibition and flexibility .

  The instructions are slightly confusing.

- The **Group Coordination** activity requires planning and sequencing – as they need to have a sequence of activities in their mind and then organize themselves into the digits as specified. Social cognition would have to be mentioned qualitatively but hard to identify unless there is a twist where people have to identify any inappropriateness in the verbal/ non verbal aspects of the skit. Or if an instruction is given to behave in an unexpected way and the actors and audience are asked to identify or report what was odd. Could be verbal or non verbal expressions of social cognition.

- The **Imagination activity** requires planning and organizing to be able to allot characters and carry out the acting. Memory would be needed for the script that is decided unless it is all impromptu. Imagination of course for a creative skit

Dr. Sunitha Shanker, consulting psychologist and psychotherapist, Mumbai.

Formerly associated with Singapore University Hospital, Somaiya hospital and medical college, Mumbai, and Ashvini Naval Hospital, Mumbai.

I have nothing to add. It has been described in so much detail - it is fantastic. The manuals and the activities for each cognitive domain are so well described. The caregiver training manual is so well written. I cannot think of anything to add or change.

Dr. Priyanka Jagtap, Psychologist, Department of Psychiatry, KEM Hospital and GS Medical college, Mumbai.

All the manuals have been very thoughtfully divided into relevant sections and have been articulated very meticulously! I really liked the fact that manual 1 mentions about focus on rehabilitation as well as cognitive retraining of the shubharthis and especially loved the concept of Hangouts Cafe. Manual 2 has elaborate details of the various activities for specific cognitive deficits and it is really impressive how the activities are graded from simple to complex levels and that activities have been included not only for the shubharthis but also for the volunteers!

Manual 3 covers all the related aspects of the disorder for the caregivers to understand especially the case vignettes and related questions based on the vignettes for a better and deeper understanding of the disorder. Module B focusing on all the basic day to day activities and how to handle the shubharthis....their behaviors, thoughts, emotions, and social cognition. and the inclusion of the REBT model for understanding the caregivers' IBs. May be we could also add somewhere about the conference organized by IPH for caregivers "What after Us?" in May 2018.....wherein the focus was on community living for the shubharthis. (*This suggestion was well received and accommodated*).

Overall, it was a fantastic read for me and added a different perspective as a MHP to looking at the seemingly basic yet complex aspects of the disorder from the caregivers point of view. Really impressive work!! Please let me know if you need me to do/give any specific inputs if required, will be more than happy.

PS: Felt elated and proud to see my Ph.D. work been acknowledged, that my work has contributed somewhere for such a great cause that will be helpful to so many people :)