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RESEARCH

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Accepting and committing to caregiving for schizophrenia—a mixed method pilot study

Aishwarjya Chakraborty[1*], Somdeb Mitra[1] and Deepshikha Ray[1]

Abstract

Background End of traditional institutionalized psychiatric care, diagnostic complexities, and associated stigma often negatively impact the social networks of caregivers, making them experience social isolation. Not the "identified patients", caregiver perspectives are typically overlooked further adding to anticipatory stigma resulting in social death among them. Caregiving experience results in developing coping skills, preventing carers from responding to the nuances of the context, and identifying the useful rules— "Experiential Avoidance". Psycho-education is typically combined with other formal treatment programs for case conceptualization, and to provide a clear rationale for the treatment approach but less as a distinct psychotherapy. Borrowing the philosophy of Functional Contextualism, the present study developed a "Present-Moment Awareness" guided psychoeducational intervention. The aim was to reduce schizophrenia caregiver burden and anticipatory stigma and promote the value of caregiver participation as 'experts by experience'.

Method Five family caregivers of remitted schizophrenia patients were recruited using purposive sampling. Pre-post measure was taken on caregiver burden, caregiving experience, sense of personal mastery, and caregiving competence. Results were analysed quantitatively and qualitatively.

Results A significant decrease in caregiver burden, stigma, and negative effects on the family in post-intervention was observed. Self-compassion led to a rise in a sense of empowerment.

Conclusion A caregiver-centred "Present-Moment Awareness" guided psycho-education for schizophrenia caregivers can be considered a possible means to address perceived stigma in caregivers and to reduce associated distress of carers.

Keywords Schizophrenia, Caregiver burden, Stigma, Psychoeducation, Acceptance and commitment theraphy

Introduction

Schizophrenia is one of the most severe and debilitating forms of mental illness which mostly follows a chronic course and impairment in social and occupational functioning [6]. The family is often the major source of care and protection for a person affected by schizophrenia [3, 7, 30] and caring for an ill relative profoundly affects the roles and interactions within the family [50]. On one hand, the responsibility of having to take care of a relative suffering for a prolonged period along with the stress of dealing with the ill relative's bizarre behaviour leads to despair, guilt [6], and helplessness [1, 7, 50]. On the other hand, there is stress associated with

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*Correspondence:
Aishwarjya Chakraborty
aishwarjyachakraborty65@gmail.com
[1] Department of Psychology, University of Calcutta, Rashbehari Siksha Prangan (Commonly Known As Rajabazar Science College Campus), 92, Acharya Prafulla Chandra Road, Kolkata, West Bengal 700009, India

social stigma [3, 15, 59], discrimination [3, 35, 59] and lack of social support [1, 3, 40] which, in turn, may lead to social isolation for the caregivers [14] and reflects how the stigma of schizophrenia results in a series of losses in caregivers' social identity, relationships, and growth opportunities [37]. According to Von Kardoff et al. (2016) [64], caregiving of a relative with schizophrenia may deplete the emotional resources of the primary caregiver, more specifically the parents, offsprings or spouses and make them susceptible to mental illness. It has been reported that caregivers of schizophrenia patients face significantly more challenges in comparison to caregivers of people living with other forms of mental diseases or chronic physical illness [31, 42]. In spite of compelling evidence that caregivers of schizophrenia suffer from stress [4], relatively less emphasis is given to the amelioration of caregiver burden [29]. It is also important to note that caregiver burden is an important predictor of recovery and quality of life in schizophrenia patients [49].

The present study thus attempts to offer an intervention programme with present-moment awareness-guided psycho-education within the Indian context and to investigate its efficacy in relation to the subjective perception of caregiver burden. It was hypothesized that the positive change in the carers' attitudes would be mainly mediated due to psychological flexibility through the awareness of their "creative hopelessness" and promote voluntary active help-seeking.

Method

Study design

The study incorporated a mixed method design, specifically a convergent-parallel design [20] where quantitative and qualitative data were collected simultaneously and independently from the same participants.

For the quantitative part of the study, a one-group pretest–posttest design was used.

For the qualitative part of the study, thematic analysis [10].

Sampling

Purposive sampling.

Recruitment

Five informal primary caregivers of patients with an ICD-10 DCR /DSM-V criteria for Schizophrenia Spectrum Disorder [5, 67] (in recovery or partial remission) participated and completed the study. The diagnosis of Schizophrenia Spectrum Disorder was made by a licensed psychiatrist from tertiary referral hospitals in and around Kolkata. The concerned patients were referred for psychological assessment /psychotherapy to the Clinical Psychology Centre of University of Calcutta.

Participants

The group consisted of four elderly parents (three fathers, one mother) of sons and a spouse of a female patient. All participants were within the age range of 18—65 years, belonging to the middle-income group as measured by Kuppuswami's Socio-economic status scale [39] with a minimum educational level of class 8. They were either a parent or a sibling or a child or a spouse to the patient of either sex and were providing care for a minimum of 1 year. The mean age of study participants was 56.8 years and the standard deviation (SD) was 11.05 (refer to Table 1 in the Results section).

Operational definition of key terms

The primary caregiver was operationalized as the person in the family most involved in the caregiving, providing time, support, monitoring medicines, and other aspects of the patient's everyday life viz. spouse, parent, offspring, and sibling.

Ethical approval

Ethical approval for the work was obtained from the Institutional Ethical Committee, University of Calcutta & Secretary, UCSTA, CU (Ref No: 015/17–18/1688). Prior information regarding the purpose of the study and confidentiality issues were communicated individually to all participants. The consent form was personally read out

Table 1 Participant characteristics

Caregiver	Sex	Age (Years)	Relation with the patient	Duration of caregiving	Socio-economic Status
Caregiver 1	Male	40	Husband	7	Lower Middle Class
Caregiver 2	Female	63	Mother	10	Upper Middle Class
Caregiver 3	Male	65	Father	10	Upper Middle Class
Caregiver 4	Male	51	Father	5	Upper Middle Class
Caregiver 5	Male	65	Father	6	Lower Middle Class

to them by the researcher in the language they understood and they were allowed to ask questions about it. As all participants hailed from a Bengali background, Bengali written consent was provided to them individually. Written consent was obtained from all the participants before the study commenced.

Tools used

1. Assessment tools

   A) *Burden Assessment Schedule of SCARF (BAS)* [60] measures the subjective and objective components of the burden across 9 different areas. Developed at SCARF with the support of the WHO SEARO & the technical support from Dr. Helmut Sell, WHO SEARO, this 40-item scale is rated on a 3-point scale. The responses are 'not at all' to 'very much'. Some of the items are reverse coded. Scores range from 40 to 120 with higher scores indicating greater burden. Inter-rater reliability (Kappa value of 0.8) [60] shows good reliability. The scale has an established criterion validity.

   B) *Experience of Caregiving Inventory (ECI)* [57] is a 66-itemed questionnaire that captures the experience of caregiving across ten subscales- eight negative subscales and two positive subscales Items are responded on a five-point Likert scale from "never" to "nearly always". The maximum score for the combined negative subscales is 208 and 56 for the positive subscales. Higher scores on the negative scales indicate greater negative perceptions of caregiving whereas higher scores on the positive scales indicate greater positive perceptions of caregiving. Each subscale has been reported to have satisfactory reliability (Cronbach alpha coefficient between 0.74 and 0.91) and the total scale (all 66 items) has also shown good reliability (Cronbach alpha = 0.93) [57].

   C) *Measure of Personal Mastery (MoPM)* [51] was used to measure caregivers' personal feelings of control over aspects of their lives. The scale consists of seven items that relate to carers' overall control of their life. Responses are coded on a four-point scale from strongly disagree to strongly agree. Five out of a total of seven items are negatively worded and two are positively worded. The negatively worded items are reverse coded prior to scoring, resulting in a score range of 7 to 28, with higher scores indicating greater levels of mastery. Total scores range from 7 (low sense of mastery) to 28 (high sense of mastery). The scale has shown satisfactory internal consistency (Cronbach alpha = 0.78) [51].

   D) *Measure of Caregiver Competence (MoCC)* [52] is a four-item questionnaire that assesses caregivers' self-competence in providing care. The four items are measured on a four-point Likert scale (total scores range from 0 to 12). A higher score indicates a higher sense of self-competence. Although more comprehensive measures are available, it was decided that a simple measure would be satisfactory for this aspect of the study as the use of more complex tools could overburden participants. A Cronbach's alpha of 0.74 [52] was reported indicating satisfactory, and statistically acceptable, internal consistency.

2. Intervention Module

Details of the assessment tools and intervention module are given below in a tabular format.

A pre-and post-assessment was conducted separately immediately before and after the intervention. After pre-assessment, participants were individually given the 11-h intervention. Each session lasted for 90 min. Participants were then interviewed after 2.5 weeks to qualitatively explore their understanding of the intervention, caregiving experience, and associated problems. Each discussion continued for 30 min. A sample size of five was chosen to determine if the study could be administered as intended. The intervention was divided into six sessions spreading over 6–7 weeks

Session	Purpose	Points Covered
Session 1	Psychoeducation	Disorder, symptoms as experienced by the patient, medication and relapse prevention
Session 2	Psychoeducation	Clarification, aetiology (neuroanatomical and expressed emotion); Formulating 'Suffering Inventory'
Session 3	Psychoeducation; Experience of Caregiver Burden	Clarification, free talk on feelings of meaninglessness, personal sacrifices, negativities of caregiving—forming; understanding the 'Creative Hopelessness' stance by means of 'Suffering Inventory' and 'Magic Wand'
Session 4–5	Management of caregiver burden; sense of moving forward rather than backward, growing rather than shrinking	Unworkability of 'Experiential Avoidance'- and 'Ball in the pool' and 'Quick sand'; Present-Moment Awareness exercise "Going Along with the Process" for "Creative Hopelessness" stance; Homework

Session 4–5	Management of caregiver burden; sense of moving forward rather than backward, growing rather than shrinking	Unworkability of 'Experiential Avoidance'- and 'Ball in the pool' and 'Quick sand'; Present-Moment Awareness exercise "Going Along with the Process" for "Creative Hopelessness" stance; Homework
Session 5–6	Increasing Present-Moment Awareness—Acceptance of the whole process	Same as previous session; feedback and homework

Rationale for Incorporating an ACT-based Psycho-education Programme

Psycho-education interventions targeted to the reduction of caregiver distress generally trys to provide information about the nature and progress of illness and about management skills. Such interventions, though effective in their own right, seldom address the emotional burden and / or burnout of the caregivers. Hence, if knowledge about the disorder is incorporated with skills related to the management of personal distress, it can be expected to be more effective in reducing caregiver burden [9]. Recent studies have provided evidence in favour of the efficacy of interventions including an education component [12, 56] and mindfulness skills in mental disorders [14, 34]. As psychological distress is a critical component of caregiving experience, induction of psychological flexibility [16] inherent in Acceptance Commitment Therapy may help caregivers detach themselves from negative experiences of caregiving [23], reappraisal of their efficacy of caregiving, de-stigmatization, and learn to live in the present. Rigidity of cognitive fusion is problematic as it results from and leads to thought patterns characterising an absolute truth [45]. Similar psycho-education modules combining ACT have been thus successfully used in schizophrenia [11].

Procedure

All the scales were translated and checked by three experts to obtain translations meaningful in the local context. The current intervention was planned and conducted by a clinical psychology trainee at the Clinical Psychology Centre of University of Calcutta (CPCUC), Kolkata, India and the intervention was supervised by two academic faculty members specialising in Clinical Psychology.

Assessment details conducted at pre-intervention and post-intervention of the study.

Session	Purpose	Points Covered
Pre-assessment	Informed consent, Rapport establishment through free talk, pre-intervention measures	Checking history of caregiving and burden as experienced, Intervention program and Mental Status Examination
Post-assessment	Post-intervention measures Discussion	Post-intervention assessment, Sharing personal experience and feedback

Analysis

Quantitative analysis

Descriptive statistics such as means and standard deviations were computed. The Wilcoxon signed-rank test was used to analyse the quantitative data as the sample size was small and the same group of participants was assessed at two different points of time [28].

Qualitative analysis

Post-assessment interviews were analysed using Thematic Analysis [10]. Investigator triangulation [24] involves the participation of three researchers; the author and her supervisors to arrive at a mutually agreed upon interpretation was done as a means of ensuring the trustworthiness of the data.

Results

Quantitative results

The significant findings on the quantitative measures are as follows-.

Table 2a shows a significant change in '*Burden Assessment Schedule*' scores from the pretest to the post-test ($p=0.042$) among caregivers indicating less burden in the post-intervention phase.

No significant change was observed in the 'experience of caregiving total negative' scores across treatment conditions ($p>0.05$). Similarly, no significant change in 'experience of caregiving total positive' scores across treatment ($p>0.05$) was observed. However, the domain-specific significant reduction in the domains of 'Stigma' and 'Effects on Family' in post-intervention was observed. Table 2b shows a significant change only in 'stigma' ($p<0.05$) and 'effect on family'($p<0.05$) scores across treatment conditions indicating less stigma and effect on family in post-intervention. Table 2c. shows no statistically significant change in 'Measure of Personal Mastery' (MoPM) ($p>0.05$) across treatment conditions among participants while Table 2d shows no statistically significant change in 'Measure of Caregiving Competence' (MoCC) ($p>0.05$) across treatment conditions among participants.

Qualitative results

Showing Focus Codes and the corresponding Open Codes for Individual Participant.

Shows Focus codes and the corresponding common components across all participant.

Tables 3 and 4 show a clear positive impact of the current intervention module on knowledge and attitude towards the illness. All participants report positive changes in the relational dynamics with the patient, a reduction in anticipatory stigma, comfortable discussing the ill-relative with others, an overall sense of empowerment, and a lookout for a better future together.

Table 2 Outcome measures

a. Burden Assessment Schedule (BAS) results among the Participants across Intervention Conditions

Variable	Mean $_{\text{Pre-intervention score}}$ (Standard Deviation/SD)	Mean $_{\text{Post-intervention score}}$ (Standard Deviation/SD)	Wilcoxon Sign Rank	*p*-value
BAS	76.80 (10.134)	62.2 (4.147)	-2.03	**< 0.05**

b. 'Domain-Specific' Scores in Experience of Caregiving (ECI) among the participants across Intervention Conditions (*Only significant results have been cited)*

Variable	Mean $_{\text{Pre-intervention score}}$ (Standard Deviation/SD)	Mean $_{\text{Post-intervention score}}$ (Standard Deviation/SD)	Wilcoxon Sign Rank	*p*-value
Stigma	7.80 (3.19)	1.40 (2.60)	-2.03	**< 0.05**
Effect on Family	13.80 (7.85)	6.60 (4.39)	-2.02	

c. Measure of Personal Mastery (MoPM) results among the Participants across Intervention Conditions

Variable	Mean $_{\text{Pre-intervention score}}$ (Standard Deviation/SD)	Mean $_{\text{Post-intervention score}}$ (Standard Deviation/SD)	Wilcoxon Sign Rank	*p*-value
MoPM	14.40 (3.28)	19.40 (4.15)	-1.22	> 0.05

d. Measure of Caregiving Competence (MoCC) results among the Participants across Intervention Conditions

Variable	Mean $_{\text{Pre-intervention score}}$ (Standard Deviation/SD)	Mean $_{\text{Post-intervention score}}$ (Standard Deviation/SD)	Wilcoxon Sign Rank	*p*-value
MoCC	7.60 (2.07)	9.60 (2.07)	-1.63	> 0.05

Discussion

The current study utilized a six-session intervention program on caregivers of people suffering from schizophrenia spectrum disorder combining psychoeducation with 'Present Moment Awareness' component of Acceptance Commitment Therapy.

A statistically significant reduction in perception of "caregiver burden", "perception of stigma", and "effect of the disease on the family" were obtained post-intervention. While knowledge about schizophrenia and alternative coping reduced caregiver burden, 'Present-Moment Awareness' helped these carers shift their focus on the overall process of caregiving, no statistically significant change in the "perception of personal mastery" and "perception of caregiver competence" was found after the intervention.

To the best of our knowledge, the current study, when conducted, was one of the few studies undertaken in India, determining the effect of Acceptance and Commitment Therapy (ACT) based psycho-educational intervention on schizophrenia carers.

Discussion on the effect of intervention on caregiver burden

The current psycho-education particularly aimed at the participant's lack of knowledge about the nature of the disorder. The illness and treatment-focused psychoeducation provided these carers with the required knowledge for problem-focused coping. Understanding patients' unpredictable behaviour and disturbances helped them to re-appraise the situation and not to interpret such behavioural abnormalities in terms of deficits in caregiving or intentional behaviour from the patient. Similar findings have been reported, where structured psycho-educational intervention is found to be more effective [56] with caregiver burden in schizophrenia [12, 46] and has significantly increased the perception of social support and satisfaction with treatment than routine outpatient care among Indian schizophrenia caregivers [3, 12, 38]. Knowledge about schizophrenia and alternative coping [17] was also found to reduce perceived caregiver burden [8]. Additionally in line with previous studies, the 'Present-Moment Exercise', which is an Acceptance and Commitment Therapy approach, helped carer's shift their focus from the burden aspect of care to the overall process of caregiving and notice when they are repetitively being self critical [63]. It was also found out that such intervention helped caregivers to deal with experiential avoidance of their caregiving related thoughts which, in turn, moderated their wellbeing and sense of burden [16, 33]. Lowered levels of experiential avoidance successfully brought down the negative effect of perceived burden, also found among family carers of people with dementia [23, 33].

Discussion on the effect of intervention on stigma

Providing care to patients with mental health problems puts a burden on families, often due to stigma [25], and moderates the use of support resources at times of need as evidenced by the qualitative data of the present study substantiated by previously established findings [55]. In line with previous studies [2], the current participants perceived societal stigma of living with a person suffering from schizophrenia led to the internalization of stigma, a condition of "affiliate stigma" [62]. It can be said that under the condition of affiliate stigma, these carers developed negative feelings toward themselves, as they identified with the stigma that prevails in society related to schizophrenia; manifested behaviourally in terms of generally engaging in less social contact,

Table 3 Focus Codes and the corresponding open codes for individual participant

Focus Code	Focus Code with Underlying Open Codes	Excerpts
	Participant 1	
Positive impact of therapy	Firm belief regarding efficacy of intervention Understanding about the nature of illness the ill-relative is suffering from Perceived efficacy of intervention regarding self as well as ill-relative The realization that the self is not responsible for the condition of the ill-relative Ability to express personal agony to other relatives Understanding that the ill-relative is not capable of sustaining long-term relationship Ability to decide on future financial empowerment for self and ill-relative Perceived sense of well-being due to intervention Confidence in discussing ill-relative's problem with other people which helps her in socialization	*"Undoubtedly it has helped, but not only regarding my son.. more about myself…..I am worried what will happen after me, If I could only get him married at least..but I don't force him anymore for marriage because for him building deep loving relationship will be very cumbersome….Now whenever there's a guest, I try to explain them…ask them not to misinterpret my son"* *"Previously I used to feel angry, resent…I couldn't speak about my pain.…I used to assure myself….felt I failed as a good mother. Now I discuss his problems with my sisters-in-law…… tell myself that I'm not responsible for his condition. I cry freely now. When others question me…I say that these are normal feelings, if others can why can't I…If I am to live with myself, I'll prefer to stay good….* *…..I am planning to open a xerox store for myself…..include son so that he can at least feed himself in future"* *"…my head feels very relaxed and light….it feels like empty…. as if my body, head and my mind are all detached…feels so relaxed, light"*
Reduced self -stigma	Ability to express personal agony to other relatives Confidence in discussing ill-relative's problem with other people which helps her in socialization	
Self-Empowerment	The realization that the self is not responsible for the condition of the ill-relative Ability to decide on future financial empowerment for self and ill-relative	
Feelings of Calmness	Perceived sense of relaxation at ease after Present-Moment-Awareness exercise	
Better shared Future	Ability to decide on future financial empowerment for self and ill-relative	
	Participant 2	
Positive impact of therapy	Perceived efficacy of intervention Perceived positive change in interpersonal relation Increased tolerance of odd behaviour from ill-relative Expressing relief in being able to share personal agony with therapist Understanding about the nature of illness and ill-relative's suffering Observation of improvement in the ill-relative Increased feeling of engagement with ill-relative & family Increased acknowledgement by the ill-relative Perceived improvement of home environment Improvement of social reciprocation of ill-relative Perceived sense of well-being after the intervention Hope for better future of the ill-relative and self	*"Previously we used to fight every day..she would suspect me…. abuse me out of suspicions.. Currently, we don't fight much, mostly I remain silent…….I understand she does not do it intentionally.. We now communicate normally….She tries to understand my struggle…the current home environment is much more normal..she appreciates my efforts."* *"Now that I am saying all these to you..as if something is choking (cry)…no one asked me how I felt…would tackle…now that you're asking and am talking…knowing why she used to behave such a way…it is so assuring."* *"* *"My biggest problem was I would not share my pain, resent internally… My colleagues suggested I admit her to an asylum, but I didn't. I never wanted her to be seen as a mad-man.. But now, I try to speak more about these issues with others….I am the problem, I am the solution. I can feel the change in me, my way of interacting….We are also suffering at the same time. We exist, I exist."* *"The exercise helps my sleep..after the exercise I feel detached, cold..as if there's pin drop off silence. My head feels so fresh… don't feel like coming back to reality"* *"I think of our travel plans. I'll be most happy if she is happy. If there's peace at home I'll perform better at work, my increments will also happen"*
Reduced self -stigma	Ability to express self to others	
Self-empowerment	Perception of self as co-sufferer	
Feelings of Calmness	Feeling of relaxation at ease after Present-Moment-Awareness exercise	
Better shared future	Hope for better future of the ill-relative and self	
	Participant 3	

Table 3 (continued)

Focus Code	Focus Code with Underlying Open Codes	Excerpts
Positive impact of therapy	Observed improvement in ill-relative's symptom and self-care Improvement of interpersonal relation between self and ill-relative Improved understanding about the nature of illness and increased ability to offering support to ill relative Perceived sense of well-being after the intervention Finding time for better self-care Feeling more energetic after breathing exercise Understanding the need to make the ill-relative empowered Increased empathy for the ill-relative Ability to see self as responsible to ensure efforts by others and ill-relative	*"I now no longer find his behaviours so difficult and irritating anymore. Of course it doesn't feel nice but after coming here I understand his behaviours……I try to motivate, provide support to him. Our understanding is better than before….I am getting peace of mind."* *"After the breathing exercise I feel relaxed..I try to find time for myself, go out regularly, walk. Talk to neighbours about what all are going with my son if they ask. I try to share my anxieties…. because of this intervention I feel more energetic, feel less down. Immediately after the exercise I feel less tensed. Ever since I am here, I try to understand others' problems similarly to the way I try to feel my son's behaviors..unlike before..I remain neutral now, when he makes mistakes….unless I deal properly, then all your efforts are in vein, my son's efforts are in vein"*
Reduced self-stigma	Ability to express agony of caregiving	
Self-empowerment	Increased ability to dissociate self from the problems Finding time for better self-care Ability to see self as responsible to ensure efforts by others and ill-relative	
Feelings of Calmness	Feeling more energetic after breathing exercise	
	Participant 4	
Positive impact of therapy	Observation of improvement in the ill-relative Perceived change in self and ill-relative due to intervention Difficulty to discuss ill-relative's problem with family and lack of family support Increased ability to support the ill-relative for betterment Improvement of interpersonal relation between self and ill-relative Perceived sense of well-being after the intervention	*" Initially I would lose calm…couldn't speak about his problems with others in case everybody comes to know. But now I remain calm, especially when I suspect he can get angry. I try to chat, share my understandings with him!"* *"I understand the treatment is time taking, probably he'll have to be medication-dependent all throughout but I'll have to keep trying. I try to provide him with mental strength, trying so that he can again start studying."* *"After the exercise I feel relaxed even when the pain remains, I feel light, his behaviours no longer hurt as much. Infact I try to keep myself busy with things outside, I feel more confident"*
Stigma and Isolation	Feelings of lack of support from outside Difficulty to discuss ill-relative's problem with family and lack of family support	
Feelings of Calmness	Feeling of relaxation at ease after Present-Moment-Awareness exercise	
Better shared Future	Hope for better future of the ill-relative and self	
	Participant 5	
Positive impact of therapy	Perceived sense of well-being after the intervention Understanding about the nature of illness and ill-relative's suffering Increased empathy for the ill-relative Accepting illness as a bad time Exploring ways to better deal with the behaviour if the ill-relative	*" I understand he thinks differently..his behaviours are not on purpose…..we understand our expectations will create more stress for him. After talking to you we now understand any quarrel, mental stress will cause a relapse….now we can discuss amongst ourselves…I try to motivate him, tell him he can't give up"* *"Yes! After coming here I do feel a change in myself……now a days I feel less angry….sad. When I get angry I go out and take a strl know we deserve a much better life, we all can be happy. I am determined I'll keep working to give him a normal life, support him….this is just a tough time'* *After the exercise, I feel detached, don't feel like coming back.. wish it could continue a little more. But yes now I can find some way out"*
Stigma and Isolation	Difficulty talking about the illness with others due to lack of understanding by others	
Feelings of Calmness	Feeling of relaxation at ease after Present-Moment-Awareness exercise	
Better shared Future	Hope for better future of the ill-relative and self	

concealing the association with the patient from the public etc. According to Mak & Cheung (2008) [43], affiliate stigma may distort a caregiver's perception of the illness and the ill relative, thereby generating greater emotional strain in the process of caregiving. Thus, internalization of stigma can be said to intensify the perception of burden in caregivers; which is also evident from the fact that "perception of stigma" is a subdomain in the scale of measurement of "experience of caregiver burden" by Szmukler et al. (1996) [57]. Werner et al. (2012) [65] had also found out that caregiver stigma increased caregiver burden in Israeli caregivers of Alzheimer's patients. Hence, it can be proposed that psycho-education incorporating information about the nature of illness

Table 4 Focus codes and the corresponding common components across all participant

Reanalysing Focus Codes Across Participants	Components
Positive impact of the intervention	Acknowledging the benefit of therapy Improvement in knowledge about mental illness Improvement in attitude toward mental illness Improvement in an interpersonal relationship with the ill relative
Reduced self-stigma	Increased ability to share personal experiences of caregiving with others Increased ability to discuss the ill relative with others
Self- Empowerment	Increased focus on self-care Future financial planning Increased ability to dissociate self from the problems
Better Shared Future	Hope for better future of the ill-relative and self
Feelings of Calmness	Feeling of relaxation at ease after Present-Moment-Awareness exercise

(schizophrenia) helps caregivers to develop and overcome the negative attitude towards the illness stemming from lack of knowledge related to the stigma; which in turn might have reduced their perceived sense of burden in caring for the ill relative. The efficacy of psychoeducation in reducing stigma [8, 35] and the subjective burden of caregiving [54, 61] has been established by previous research.

From a different perspective, psychological inflexibility is associated with self-stigma [13]. Hence, the incorporation of ACT may help the participants (caregivers of persons suffering from schizophrenia) develop the ability to "engage in valued behavior by remaining open to internal experiences" [36], which, in turn, may serve to lower levels of stigma. Mak et al. (2021) [44] also reported that ACT helped caregivers to accept the inevitability of the difficulties associated with caregiving of a relative suffering from a psychiatric disorder, reduced their (caregivers) reliance on experiential avoidance, and repression of negative feelings which probably acted as resistance to stigma, and promoted their recovery.

Discussion on the effect of intervention on the effect on family

The relationship between perceived stigma and the severity of caregiver burden of schizophrenia is observed to be mediated by the caregivers' experience of the effects schizophrenia has on the family, and other social functioning. Experiential avoidance of such unpleasant emotions might lead to a vicious circle of intensifying the negative emotions. The present-moment awareness used in this study allowed the caregivers to relate to their thoughts differently [58]. Post-intervention, the perspective of the caregivers on the negative effects of schizophrenia on the family changed. Their awareness of the moment at present opened them to commit to behaviours deeply rooted in caregiving values that ultimately reduced the impact of schizophrenia on the family and provided an integral approach to schizophrenia, as evidenced by both previous literature [26] and the current findings of the study.

Discussion of findings from qualitative study

It is evident from the findings of the qualitative part of this research that the caregivers experienced self-blame and lack of self-compassion prior to the intervention and reported improvements in these domains after the intervention [21, 22]. Previous studies have also been able to find quantitatively measurable associations between self-compassion, psychological flexibility and mindfulness [18, 19] which were components of the ACT incorporated within the psychoeducation program. According to their narrations, the caregivers, after receiving the intervention could consciously (mindfully) acknowledge their stigma and reappraise their role as a caregiver, accepting their experiences of distress as a natural consequence of caregiving. Similar efficacy of integrating mindfulness with traditional psychoeducation in the reduction of caregiver burden was obtained by Neff & Germer (2013) [47] and Zhang et al., (2023) [68].

The qualitative data also reveals a marked change in the nature of expressed emotion of the caregivers. The intervention program used in this study included "mindfulness" which helps clients (caregivers) to directly address their painful emotions and thoughts and thereby develop a positive self-appraisal [48]. Such a practice could have helped the participants (caregivers) to grow more understanding and compassionate towards themselves as they encountered the challenges of caring for their relatives with schizophrenia. Again, such acts of kindness towards self are also empowering in the sense they may act as a buffer against the emotional toll of caregiving, foster positive self-appraisal and a non-critical attitude towards oneself [66], leading to reduced feelings of caregiver burden. A study by Goodridge et al. (2012) [27] had also been able to show the effectiveness of "mindfulness-based self-compassion program" to enhance the emotional well-being of the participants who happened to be.

Conclusion

To the best of our knowledge, our study when conducted was one of the few studies undertaken in India, determining the effect of Acceptance and Commitment Therapy (ACT) based psycho-educational intervention on schizophrenia carers.

Helping the caregivers view themselves, the patient, and the future compassionately helps caregivers endure the burden of the present situation, and strengthen their value-directed behaviour. Fostering future hope is particularistic as well as general. Hope and family involvement are related to socio-cultural, age, economic, and geographical contexts. This might prompt in the future for the provision of family-focused brief ACT-based therapy and the role of social prescribing as a mandatory treatment module. However, such aims can only be achieved by systematically including informal caregivers as active partners, in treatment and research. Carers are 'experts by experience' just as patients are. Without their voices, the picture remains incomplete. Involving informal carers is an important means to address social expectations; to rethink the existing hierarchies of the current Indian health-related science and thus change the treatment culture as a whole.

Limitations

One major limitation of this study was the small sample size with primarily elderly caregivers. No matched control group was included. A randomized waitlist control group, dynamic waitlist design (DWLD), and regression point displacement (RPDD) as alternatives could have increased the efficiency and generalization power of the study findings. Availability of caregivers was a major restriction due to the lack of an in-patient facility at the study centre coupled with stigma toward family intervention. Also, attending a family program conveyed a series of monetary and logistical difficulties including time, motivation, and energy.

Future implications

A major observation and an impediment faced while carrying out the study was the lack of willingness for families to be active participants in treatment due to the existing social stigma related to mental health. The exact interconnection and frequency of real and anticipated stigma in India needs clarification [26]. Further studies similar to the current study should specifically focus on developing self-compassion-based psycho-educational intervention using cognitive defusion and present-moment awareness skills. It will be worth observing how the current intervention may promote psychological resilience and mindful self-compassion [32, 41] along with reducing caregiver burden [53] and affiliate stigma [62].

The general understanding of the need for collaborative family-based intervention to mainstream patients was poor. Families often approach therapy as an individual endeavour and not as a collective phenomenon. While the attitude towards the development of any mental illness is a failure on the part of the affected individual, similarly cure is often perceived as the patient's responsibility. Thus, it is essential to deeply explore the role of Indian collectivism in promoting social security and how the prevailing paternalism outweighs quality healthcare. From a treatment perspective, more than reducing actual stigma, the focus should be on how to normalize perceived discrimination and thus reduce the social death of these families. Further qualitative research is required to study these overlapping pathways between the mental bias of experiential avoidance and decision-making to curate human-centric interventions.

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Author's contributions
The study was designed by A.C and supervised by S.M and D.R. A.C conducted the study, collected and analysed the data, and prepared the first draft of the manuscript. S.M and D.R supervised the data analysis and writing of the final draft of the manuscript. All the authors read the manuscript and approved it.

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Availability of data and materials
The data that support the findings of this study are available from the 1st author (corresponding author), but restrictions apply to the availability of these data and are not publicly available. The data are, however, available from the author upon reasonable request and with the permission of the university's ethical committee.

Declarations

Ethics approval and consent to participate
Ethical approval for the work was obtained from the Institutional Ethical Committee, University of Calcutta & Secretary, UCSTA, CU (Ref No: 015/17–18/1688). Prior information regarding the purpose of the study and confidentiality issues were communicated individually to all participants. The consent form was personally read out to them by the researcher in the language they understood and they were allowed to ask questions about it. As all participants hailed from a Bengali background, Bengali written consent was provided to them individually. Written consent was obtained from all the participants before the study commenced.

Consent for publication
Not applicable.

Competing interests
The authors declare no competing interests.

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