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Research Article

Group Compassion-Focused Therapy for Psychological Distress in Parkinson's – An Exploratory Case Series in Clinical Practice

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Abstract

Objectives: To develop and evaluate a novel compassion focused therapy (CFT) group intervention to alleviate distress for people with Parkinson's, delivered in clinical practice. **Methods:** A CFT group was designed and 4 people took part as part of their clinical care. After modifications based on feedback a second group (again with 4 people) then took place. Pre-, post- and follow up measures for both groups were administered and analysed using reliable change. Interviews with participants were completed and data analysed using thematic analysis. **Results:** Based on experiences in the 1st group (6 weeks), the 2nd group was longer (8 weeks) and a cognitive screen was introduced to ensure participants could access the material. Experiences of the groups were generally positive; participants valued meeting others with Parkinson's and developing new compassion-focused skills. One task was reported as too confusing. Some participants experienced changes in anxiety, depression, stress and wellbeing. The mechanism of change was uncertain as there were few changes in the predicted mechanism of self-compassion. **Conclusions:** A CFT group of 8 weeks was acceptable to people with Parkinson's and has the potential to alleviate distress. Cognitive ability needs to be carefully considered. Further research is now needed to develop the intervention and proceed to a more stringent evaluative study.

Keywords: self-compassion, compassion-focused therapy, compassionate-mind training, Parkinson's disease

Introduction

Parkinson's disease (hereafter Parkinson's) is a neurodegenerative condition characterised by tremor, stiffness, slowness of movement and gait problems. It often includes other difficulties including with pain, sleep, incontinence, fatigue, swallowing and drooling [1] and mild cognitive impairment is also relatively common [2]. Moreover, anxiety and depression each affect around a third or more of people with Parkinson's [3,4].

Medication prescribed for psychological difficulties is not always effective and, in order to widen treatment options, psychological therapies for people with Parkinson's are beginning to be developed and trialled [5]. Cognitive behavioural therapy has the most robust evidence to date with promise also for mindfulness interventions [6]. However, relatively little research exists and with the rising number of older people and a desire for psychological intervention [7] it is important to develop further approaches.

Compassion focused therapy (CFT) was originally developed for working with shame and self-criticism for those experiencing complex mental health problems [8]. The therapy aims to find balance between three affect-regulation systems focused on threat, drive/excitement and soothing/safeness and focuses on accessing the soothing system when individuals encounter threat. Evidence is promising for the effects of CFT on low mood and anxiety in general population samples and those with mental health difficulties [9-12].

Managing Parkinson's is stressful, with deteriorating physical functioning, deteriorating medication efficacy and troublesome side effects. People also experience stigma and changes in identity [13-16]. Shame can arise due to physical symptoms, reduction in independence and lower satisfaction with body image [17]. People with Parkinson's often compare themselves negatively to others, or their 'previous self' [18]. Such difficulties can also be exacerbated by self-blame or self-criticism for not meeting self or others' expectations [19].

Developing self-compassion may offer a way to ameliorate some of these difficulties. Self-compassion is associated with less stress, depression and anxiety for people with Parkinson's [20,21]. Greater self-compassion may be associated with better self-regulation [22], including more adaptive forms of coping [23], which are key for reducing anxiety and depression in Parkinson's [24]. Self-compassion may help reduce self-blame in chronic illness [22], as well as reducing shame associated a with changing body and changing abilities [25,26].

Meta-analyses suggest CFT for distress in chronic illness is effective [27] but the size of effects are uncertain and may differ from mental health populations [28]. However, many studies have not investigated self-compassion as the mechanism of change, or have focused solely on meditation rather than a range of self-compassionate techniques and tasks. Importantly, only one study on neurological conditions was included in each review. A recent pilot randomized controlled trial (RCT) for chronic illness compared online CFT with acceptance and commitment therapy [29] and found both were acceptable. However, there was significant dropout and again, few or no participants had neurological conditions. CFT has been studied with people with brain injury [30], but this was in an inpatient rehabilitation setting and combined a mixture of individual and group interventions. More recently CFT has been piloted with people with dementia, both individually [31] and in a group with partners [32], which have indicated how CFT may be adapted to take account of significant cognitive difficulties. However, the effects of group CFT in an outpatient setting on psychological distress experienced by people with Parkinson's is unknown.

Consequently, this study presents the development and use in clinical practice of a novel face-to-face CFT group for people with Parkinson's experiencing psychological distress.

Method

Design

The CFT groups took place as part of service development of the Parkinson's service, and participants received the intervention as part of clinical practice. The pre- and post- measures were therefore collected as part of participants' routine care, to monitor the impact of the intervention on the individuals, including learning of self-compassionate skills and behaviours, and to inform service development. Following the intervention, interviews were conducted with participants aimed at finding whether the intervention was acceptable for people with Parkinson's experiencing distress, and what changes might be needed, again to inform service development .

Recruitment

Participants were all accessing the Cardiff and Vale University Health Board Parkinson's Disease Service. Two groups took place (see below). Inclusion criteria were: diagnosis of idiopathic Parkinson's; elevated scores/scores in the clinical range on at least one main outcome measure; absence of significant risk concerns; willingness to engage in a group intervention; no previous experience of CFT. For the second group the additional criterion of cognitive capacity to engage, assessed using the mini Addenbrooke's cognitive examination (mini-ACE) [33] was added.

Patients who met the inclusion criteria were offered the intervention. Ten people were offered the first group and four accepted and took part. Eleven were offered the second group and five accepted and started the group. One left after three sessions and hence data are available for four participants. One participant from the first group was unable to participate in an interview due to cognitive decline. It should be noted that small group sizes like these are not unusual in CFT [34].

Ethics and Consent

As this study presents data collected and analysed during routine clinical practice in one UK service, the UK Health Research

Authority and host National Health Service (NHS) Health Board classed the project as a service evaluation rather than research and so ethical approval was not required [35]. The service evaluation received the appropriate governance approvals from the host NHS Health Board. All participants gave written consent for their data to be used in the service evaluation and published.

Intervention

The intervention content was informed by CFT training undertaken by the service clinical psychologist and relevant resources, e.g., https://www.compassionatemind.co.uk/resource/resources (see Tables 1 and 2). Four brief video clips were developed with people with Parkinson's and medical colleagues which contained CFT theory tailored for people with Parkinson's. These aimed to make the material more accessible and relevant.

Following participant and facilitator feedback from Group 1, the following changes were made for Group 2. A screen for cognitive difficulties was administered; the number of sessions increased from 6 to 8; more mindfulness-based activities were included and the follow up timeframe increased from 6 to 8 weeks. Groups were facilitated by a clinical psychologist and trainee clinical psychologist.

Session 1	**Compassionate mind for Parkinson's:** Definition of compassion, old and new brain, case study discussed and psychological impact of Parkinson's. Session ended with 4 and 6 breathing exercises.
Session 2	**The three emotion systems**: The three emotions systems, focus on the threat system and what it may look like for people, discussion around how anxiety feels in the body. Exercises practised: 5-4-3-2-1 grounding exercises and 3 minute body scan.
Session 3	**The three emotion systems (continued)**: The three emotions systems recapped and particular focus was given to the drive and soothing systems - group discussion on activities that could be done during the week to activate these systems. Box breathing and body scan practised.
Session 4	**Being compassionate towards ourselves**: Self-compassion and the barriers to self compassion and how we respond to others suffering vs ourselves. Mindfulness with a compassionate phrase exercises was practised.
Session 5	**The many parts of you**: Practised mindfulness with a compassionate phrase exercise. Session covered the different parts of us and the emotions people with a diagnosis of Parkinson's may experience. Practised the safe space imagery exercise in the session.
Session 6	**Summary and looking forward**: Summary of previous sessions. Activity planning around activities or strategies to activate soothing and drive systems. Three-minute body scan practised within the session. Second half of the session was spent completing mood and self-compassion related questionnaires.
6-week follow up	**Consolidation:** Reconnected with concepts and skills learnt. Discussed how these had been put into practice. Completed questionnaires.

Table 1: Weekly schedule for group 1

Session 1	**Compassionate mind for Parkinson's**: Definition of compassion, old and new brain, discussion around the psychological impact of Parkinson's. Session ended with 4 and 6 breathing exercises.
Session 2	**The three emotion systems**: The three emotions systems, focus on the threat system and what it may look like for people, discussion around how anxiety feels in the body. 5-4-3-2-1 grounding exercise practised.
Session 3	**The three emotion systems (continued)**: The three emotion systems, with discussion particularly around the threat and drive systems. Discussion around the group members emotions systems and what they look like. Box breathing and body scan practised.
Session 4	**The many parts of us**: Discussions around the critical and compassionate selves and the different parts of us. Practised soothing rhythm breathing and invited people to personalise compassionate statements for themselves.
Session 5	**Introduction to compassion and sleep hygiene**: Discussion of compassionate statements and sleep hygiene. Grounding exercises practised: clenching and releasing fist & tapping (opposite shoulders). Loving kindness meditation with compassionate phrases also practiced.
Session 6	**Being compassionate towards ourselves and mindfulness**: Mindfulness and the rational behind mindfulness discussed. Barriers to self-compassion discussed, exercise practised was progressive muscle relaxation.
Session 7	**Embodying self-compassion**: Mindfulness activity with everyday object practised. Flows of compassion discussed and what strands people find easier than others. Barriers to compassion exercise. Breathing with mindfulness element practised.
Session 8	**Summary and looking forward:** Recap of previous sessions and a discussion around what has been helpful and unhelpful. Compassionate letter writing. Psychometrics and qualitative feedback collected.
8-week follow up	**Consolidation:** Reconnected with concepts and skills learnt. Discussed how these had been put into practice. Completed questionnaires.

Table 2: Weekly schedule for group 2

Outcome measures

Wellbeing was measured using the Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS; [36]; Cronbach's α = 0.91). Higher scores indicate greater well-being. Anxiety was measured using the Parkinson's Anxiety Scale (PAS; [37]; Cronbach's α = 0.89). A total score of 14 or higher is congruent with an anxiety disorder. Depression and stress were measured using the short-form of the Depression, Anxiety and Stress scales (DASS; [38]; Cronbach's α depression = .94, stress = 0.91), with scores doubled to equate to the full scale [38]. Higher scores indicate higher distress.

Process measures: Self-compassion

Self-compassion was measured using the Self-Compassion Scale - Short Form (SCS-SF; [39]; Cronbach's α = 0.86) and the Sussex Oxford Compassion Scale – Self (SOCS-S; [40]; Cronbach's α = 0.91-0.93). Higher scores indicate greater self-compassion.

For group 1 all measures were administered pre- and post-intervention and the PAS, WEMWBS and SCS-SF were administered at follow up. For group 2 all measures were administered pre-intervention, post-intervention and at follow up.

Qualitative interviews

A semi-structured interview schedule (adapted from [30]) asked the participants what they found helpful or unhelpful, how easy the concepts were to understand and put into practice, how they found the group setting and whether it had any impact on their psychological difficulties. Interviews were conducted 3 months after group 1 and before the follow up session for group 2.

Analysis

Six separate questionnaires were missing one item on a scale and the scores for these items were pro-rated. Reliable change indices were calculated for each participant for each measure, comparing post-intervention and follow up scores with pre-intervention scores [41]. Qualitative data were analysed by thematic analysis [42].

Quantitative results

Data for each participant are given in Table 3. Demographics are described below, but given in a group format to aid anonymity.

	PAS			DASS Depression			DASS Stress			WEMWBS			SCS-SF			SOC-S			No. sessions
Ppt	**Pre**	**Post**	**F up**	**Pre**	**Post**	**F up**	**Pre**	**Post**	**F up**	**Pre**	**Post**	**F up**	**Pre**	**Post**	**F up**	**Pre**	**Post**	**F up**	
Grp1																			
1	27	14*	32	34	28	-	32	30	-	41	41	33	3.09	3.00	3.00	67	62	-	5/6
2	22	**13***	-	10	8	-	14	11.7	-	44	46	-	2.83	4.17*	-	-	-	-	5/6+f up
3	21	26	**11***	14	28†	-	18.7	28†	-	44	44.8	45	3.00	2.83	3.17	65.6	64	-	3/6
4	18	-	21	20	14	-	24	12*	-	37	46	46	2.33	2.17	3.00	71	68	-	5/6+f up
Grp2																			
5	19	21	**6***	26	16*	18*	34	18*	20*	54	42†	54	2.50	3.00	3.17	-	66	76	7/8
6	23	23	33†	18	12	20	26	14*	12*	38	50*	38	3.08	2.75	2.92	71	64	63	7/8+f up
7	27	**5***	**12***	26	16*	12*	12	6	8	41	43	42	2.25	2.83	3.25*	46	58*	57*	8/8
8	32	28	24	38	42	40	30	42†	34	23	60*	40*	2.58	2.83	3.25	63	60	78*	7/8+ f up

Ppt participant number; PAS Parkinson's Anxiety Scale; DASS Depression, Anxiety and Stress Scales; WEMWBS Warwick Edinburgh Mental Wellbeing Scale; SCS-SF Self-Compassion Scale – short form; SOC-S Sussex Oxford Compassion Scale – self subscale; No. sessions number of sessions; Grp Group; F up Follow up; Bold = below clinical cut off on PAS; * = reliable improvement; †=reliable deterioration. For reliable change calculations data were taken from [20]; [37]; [21]; [36].

Table 3: Scores and reliable change

Group 1 (6 weeks)

Participants were 2 men and 2 women aged 61-69 diagnosed with Parkinson's 3.5-8 years ago. All had been referred for help with anxiety and all scored above the clinical cut-off for the PAS. DASS depression scores pre-intervention were very severe (N=1), moderate (N=2) and mild (N=1); DASS stress scores were severe (N=1), moderate (N=2) and none (N=1).

Three participants (1, 2 and 4) who attended 5 out of 6 sessions, had some reliable improvement in some measures.

Participant 1 had reliable decrease in anxiety post-intervention but this increased again at follow up. There were no significant changes on other measures.

Participant 2 also had reliable decrease in anxiety post intervention and this moved below the clinical cut-off, and had reliable change in self-compassion. Follow up scores were missing.

Participant 4 had a reliable decrease in stress post intervention (from moderate to none), but no other reliable changes.

Participant 3, who attended 3/6 sessions, had no change in anxiety post-intervention but reliable decrease at follow up and the score was then below the clinical cut-off. However, depression and stress had reliably worsened post-intervention (not measured at follow up). Due to cognitive difficulties this participant struggled with the group pace and so had one additional separate session with their partner and the clinicians before the final group session to help them access the material.

Group 2 (8 weeks)

Participants were 1 man and 3 women aged 62-78 diagnosed with Parkinson's 1.5-5 years ago. Three were referred for help with anxiety and one for adjustment and all scored above the clinical cut-off for the PAS. Pre-intervention DASS depression scores were moderate (N=1), severe (N=2) and very severe (N=1) and DASS stress scores were none (N=1), severe (N=2) and very severe (N=1). Three participants attended 7 sessions and one all 8 sessions.

Participant 5 had a reliable decrease in anxiety at follow up only and their score moved into the non-clinical range. Post-intervention and follow up they had a reliable decrease in depression (severe to moderate) and stress (very severe to mild to moderate). Inconsistently, there was a reliable decrease in wellbeing post-intervention but this increased to no change at follow up.

Participant 6 had a reliable decrease in stress at both time points (severe to none), a reliable increase in wellbeing post-intervention only but a reliable increase in anxiety at follow up only. No changes in depression were seen.

Participant 7 had a reliable decrease in anxiety at both time points and their score moved into the non-clinical range. They also had reliable decrease in depression at both time points (severe to moderate to mild) and reliable increase in self-compassion post-intervention and follow up. Stress did not reliably change but was low pre-intervention.

Participant 8 had a reliable increase in wellbeing at both time points and a reliable increase in self-compassion at follow up. There was a reliable increase in stress post-intervention but this reduced again at follow up. No reliable changes were seen in anxiety or depression.

Qualitative results

Four themes, with subthemes, were generated from the data. One theme focused on psychological distress and lack of psychological support for people with Parkinson's generally, which is widely known [6, 43, 44] and is therefore not reported here; the three reported themes relate to the group content and process (see Table 4).

Main themes	Sub-themes
A well accepted approach	Overall appreciation Learning and practising self-compassion It's made a difference
Learning and connecting with others	Learning from each other The value of group connections and relationships
Making CFT make sense	Getting the right time Number of group sessions Complexity of the material Follow up groups

Table 4: The three main themes and sub-themes identified in the thematic analysis

Theme 1: A well accepted approach

Overall appreciation: Participants spoke positively about the group overall:

"*I wish I could go back again... I really, really enjoyed it."*

"... it seems a good idea, definitely worth doing."

Learning and practising self-compassion: Participants appreciated learning and applying specific aspects of the CFT approach.

"I didn't realise about say, the fight or flight thing, the soothing system. I wouldn't really have been aware of how they fitted into Parkinson's…"

It would have taken me a long time to be, what can I say, kind to myself... it's not me, it's Parkinson's causing the problem, and relax a bit more and enjoy life."

"I still have emotional difficulties, but I'm more kinder to myself, so I can accept them, and think, well tomorrow I'll be a lot better, and try and be mindful of relaxing and being very very kind to myself."

It's made a difference: Most participants felt that the group had made a positive difference in their lives.

"…beforehand I would have realised what, how my emotional state was, but I don't necessarily think that I realised how I could reduce the anxiety and feelings of being anxious. But it's, now, you've given me the tools to, to deal with it, and I know why I feel that way, so it has been very, very positive."

"It has helped me quite a bit I think, I am able to go out more now with my husband, I do think back [to] the group when I do feel anxious."

Theme 2: Learning and connecting with others

Learning from each other: Participants valued the group nature of the intervention and learning from each other's experiences and contributions.

"And each and every one of them brought little things that were like little gems, thinking, I'd never even thought of that."

"terribly keen... to try to learn from, from other people and, what sort of between way people process things. There's always things that, to, to learn, however difficult situation is you're in."

The value of group connections and relationships: All participants valued the connections and relationships, which could reduce the sense of being alone with Parkinson's.

"It was very nice getting to know another, a new group of people. And, because I think that's the one thing I take from Parkinson's, from diagnosis onwards, is it's isolating because there's not much known about it... so it's nice meeting new people."

"From the outside you can't see that I'm suffering so much inside. And there are people, they know how much I'm suffering inside... such a big consolation."

Theme 3: Making CFT make sense

Getting the right time: For CFT to make sense, it had to be delivered at the right time for people. Some participants felt that receiving support sooner following diagnosis would have been beneficial, whilst others felt it had arrived at the right time for them.

"...it should come a lot earlier… I would have found this course, or the choice of going on this course, a lot more helpful early on in the diagnosis."

"The strategies have been, have come at the right time really."

Number of group sessions: The number of sessions was also important for the intervention to make sense. Participants in the six-week group appeared to feel that the group had been too short, whilst participants in the eight-week group appeared more content with the number of group sessions.

"I felt by the time we were, we just got going when we were rounding it up really." (6 weeks)

"…when we started doing the group, obviously we didn't know what to expect, and I think the more we went and the more we were involved with it, it made us more relaxed…" (8 weeks)

Complexity of the material: Some group members felt that some of the material was too complex. This was mainly in relation to particularly abstract concepts, such as writing a compassionate letter to the critical part of themselves.

"… I wrote a letter to myself. Which is extremely difficult to do. I wasn't altogether clear, you know, what exactly I was saying, you know, a letter of advice, or you know, or what it was."

"I found quite a lot of it difficult to understand and also sometimes I thought it was quite heavy, but I did understand quite a bit of it, yeah."

Follow-up groups: Many participants felt they would value ongoing follow-up sessions with their group to maintain connections and skills.

"Contacts perhaps quarterly, something like that to sort of say well we've got another course, or an update, or a, or a Zoom call or whatever we'd like you to perhaps participate in, is welcomed."

"I think it would be very nice if they kept up a group and helped, every so often, the group to meet and be able to chat about how they've progressed."

Discussion

The qualitative findings from these two CFT groups were largely positive, conveying acceptability of the intervention, including the self-compassion information and tailoring of materials to Parkinson's. The attendance rate was high, particularly compared to recent online trials of CFT in chronic health [29] and in-person mental health settings [34], again showing the acceptability of the group.

The 8-week programme (group 2) gave participants more time to become socialised to the model, understand the concepts and share experiences. While group 2 excluded individuals with more severe cognitive problems, the longer timeframe still appeared necessary to enable new concepts to be learnt. Similar adaptations to CFT such as more sessions, using visual diagrams, repetition and slowing down the presentation of material, as well as text reminders, have been used with people with brain injury [30, 45] or dementia [31,32]. Even for group 2, one of the tasks (compassionate letter writing) was too complex for people to grasp and therefore future groups may need to use a different more concrete task to develop further their self-compassionate skills.

Being and learning with others was particularly valued. Participants experienced reduced isolation and individuals learnt from each other – benefits often seen in other group interventions for people with Parkinson's [46,47]. The importance of the self-compassion mechanism was less clear. Very few reliable changes were seen in the self-compassion measures, even when changes were seen in distress outcomes. This may be partly due to the relatively strict criteria for reliable change, as several participants' scores did improve on the SCS-SF, and the qualitative data suggested participants were using some of the concepts and skills. In addition, the effect size of such changes may only be small [36]. Further research would need to explore participants' understanding and application of the skills in more depth and could also explore other possible mechanisms, e.g. changes in self-criticism, emotional regulation, stigma, and social connectedness.

While all participants had clinical levels of anxiety pre-intervention, the group addressed distress more generally and it was beneficial for some for a variety of outcomes. Given that individuals are likely to experience more than one type of difficulty [48], an intervention that targets a process which could

be relevant for anxiety, depression and stress simultaneously makes it a potentially practically useful intervention for services and transdiagnostic groups have been run in mental health settings [34].

Most participants had some ongoing difficulties and wanted further follow up sessions to help re-connect with others and re-emphasise the skills. Other psychotherapeutic models with similar neurodegenerative conditions have found having additional reunions or check in sessions were beneficial [49-51], and where resources allow this might be a helpful addition to the intervention.

Considering limitations, as a small case series, conclusions cannot be drawn about the efficacy of the approach, which would require rigorous clinical trial investigation. Investigating the feasibility of such would be the next step [52]. The interviewer for the qualitative findings was also a facilitator for Group 2 which could have biased in the participants' responses. The data for the person who left could not be collected, so their experiences are not represented.

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Data availability: Given this study was conducted in clinical practice, the participants of this study did not give written consent for their data to be shared publicly, so due to the sensitive nature of the research supporting data are not available.

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