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A pilot trial of Moderated Online Social Therapy for family and friends of young people with Borderline Personality Disorder features

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Abstract

Aim: We evaluated the acceptability, usability and safety of Kindred, a novel online intervention for carers of young people with borderline personality disorder (BPD)using a pre-post pilot trial design. The secondary aim explored whether Kindred use was associated with clinical improvements for caregivers on measures of burden of caregiving, stress, expressed emotion, family communication, disability, coping and knowledge of BPD and for patients on measures of severity of BPD symptoms and level of functional impairment.

Method: The trial site was the Helping Young People Early (HYPE) program for young people with BPD at Orygen in Melbourne, Australia. Informed consent was obtained from 20 adult carers (i.e., relatives or friends) and 10 young people aged 15 to 25 with BPD. Kindred, which was available for 3 months, incorporated online psychoeducation, carer-to-carer social networking, and guidance from expert and peer moderators. Assessments were completed at baseline and 3 months follow up. Multiple indicators of acceptability, usability and safety wereutilized.

Results: Seventeen carers were enrolled in Kindred and 8 young people completed baseline measures. *A priori* acceptability, usability and safety criteria were met. Carer burden, stress, expressed emotion, family communication, quality of life, functioning, coping, and perceived knowledge of BPD improved at follow-up. Sixty-six percent of the young people (4/6) reported that they believed Kindred had improved their carers' understanding of BPD.

Conclusion: Kindred was shown to be acceptable, usable and safe, with encouraging improvements in both carer and young person outcomes. Kindred warrants evaluation of its efficacy via an RCT.

Key Words: Adolescent; Borderline Personality Disorder, Carer, Early intervention, Online treatment

Short running title: Online therapy for carers of young BPD patients

1.Introduction

Borderline personality disorder (BPD) is a severe mental disorder that is characterised by extreme sensitivity to perceived interpersonal slights, an unstable sense of self, intense and volatile emotions and impulsive behaviours(Gunderson et al., 2018). The clinical ‘onset’ of BPD is typically in the period between puberty and emerging adulthood (young people; aged 12 to 25 years) (Chanen & Thompson, 2019) and consensus BPD guidelines explicitly recommend early diagnosis and treatment (Chanen et al., 2017).

Carers[1]of people with BPD experience the greatest severity of burden relative to other family psychiatric populations (Bailey &Grenyer, 2013; Seigerman et al, in press). As reported in a recent systematic review (Sutherland et al., 2019), non-randomised pre-post studies, with small sample sizes, of carers of individuals with a personality disorder, have demonstrated a reduction in caregiver burden. However, the two recent randomized controlled trials (RCTs), each comparing active psychoeducation with a wait list control did not demonstrate a treatment effect for burden of caregiving(Bateman &Fonagy, 2019; Grenyer et al., 2019). These studies primarily recruited adults with BPD and, therefore, the findings have limited generalizability to carers of young people in the early stages of BPD.

Early intervention for young people with BPD, including support for carers, is designed to prevent or reduce the severity of long-term problems with social functioning (Chanen et al., 2017). Members of our group have developed and evaluated the only intervention programs specifically for carers of young people with BPD features: the face-to-face *MS-BPD psychoeducation group program*(Pearce et al., 2017) and two *Online* modules, *Introduction to*

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[1] We acknowledge that some people object to the term “carer”. We use the term here without intending any disrespect.

Early Intervention for Borderline Personality Disorder and *Caring For a Young Person with Borderline Personality Disorder - Information for Families and Friends*(Betts et al., 2018).

The pre-post pilot evaluation of MS-BPD showed a reduction in subjective burden in 29 carersand an increase in perceived personality disorder knowledge. Building on these findings, an RCT was conducted with 79 carers of young people with BPD features to evaluate MS-BPD + Online (38 carers from 28 family units) compared with Online alone (41 carers from 30 family units). There was no difference between the treatment groups with regards to rate of change for caregiving burdenseven weeks after commencing the intervention(s).

Two major issues are notable when interpreting these findings. First, fifty three percent (94/178) of eligible carers declined to participate in the RCT. The most common reason for non-participation was the perceived inconvenience of attending face-to-face sessions (n=60, 63.9%). Seecond, the ‘dose’ of MS-BPD (being just 3 x 2-hour sessions over 15 days) is also likely to have been inadequate to produce a significant effect.

In light of these issues, we have developed a model of online intervention for carersbased on the Moderated Online Social Therapy (MOST) framework(Gleeson et al., 2017). The MOST web platform integrates, within a single online application, private social networking, psychoeducation, and specialist and peer moderation. Building on the knowledge generated from our two previous carer trials (Betts et al., 2018; Pearce et al., 2017), we developed the online Kindred MOST application to support carers of young people with BPD features.

The aim of the current pilot study was to evaluate the acceptability, usability and safety of Kindred in addition to exploring whether the use of Kindred is associated with changes for carersin caregiver burden, stress, expressed emotion, family communication, quality of life, functioning, coping, and perceived personality disorder knowledge and with changes in the severity of BPD and functional impairment among the young people with BPD features.

2. Method

2.1 *Study design*

This pilot trial was a pre- and post-intervention, repeated measures design. The trial was conducted by Orygen, and The Australian Catholic University. It was approved by the Melbourne Health Human Research Ethics Committee (HREC /17/MH/254). The trial was funded by an Australian Catholic University Program Grant and was prospectively registered (ACTRN2618000616279).

2.2 *Study setting*

The study was conducted at the HYPE early intervention program for young people with BPD (Chanen et al., 2014) at Orygen. HYPE provides specialist mental health care for young people (aged 15 to 25 years, inclusive) residing in northwestern and western metropolitan Melbourne, Australia, who meet ≥3 DSM-5 BPD criteria.

2.3 *Inclusion and exclusion criteria*

Carer participants were: (i) relatives, legal guardians, or friends of a current HYPE client; (ii) aged ≥ 18 years; (iii) able to read and converse in English; and (iv) having a minimum of weekly contact with their young person. Exclusion criteria were (i) involvement in current legal action against the young person; or (ii) no access to the Internet or an appropriate device. Young person participants were: (i) currently registered for care with HYPE, and (ii) were able to read and converse in English.

2.4 *Procedure*

Participants were recruited between June and September 2018. Written informed consent was obtained from all participants aged 18 years and above, and additionally from a parent or guardian for those younger than 18 years. Carer and client participants completed a baseline assessment comprising of an interview and self-report measures. Following the baseline assessment, carers were orientated to Kindred which was accessible for users between August and November 2018. Follow-up assessments with carers and young people were conducted 3 months after the carers commenced Kindred. Participants received a small cash reimbursement for costs incurred in the baseline and follow-up assessments.

2.5 *Interventions*

Kindred was designed to support the carers of young people with BPD features, who are in early-stage BPD. Its development was informed by principles of the HYPE model of care and CAT, which places the emphasis upon BPD as a relational disorder (Chanen et al., 2014). Using a purpose-built online digital platform (MOST) (Lederman et al., 2014), Kindred enables the delivery of: (i) psychoeducation and therapy, (ii) carer-to-carer social networking, and (iii) input from expert and peer moderators.

The psychoeducation and therapy component addressed distinct themes, e.g., understanding BPD, communicating with their loved one, self-care, emotional well-being, and mindfulness for carers. The content was specifically designed to improve carer burden and stress, e.g., by encouraging self-care and facilitating carer self-efficacy.

The carer-to-carer online social networking occurred via the ‘cafe’ newsfeed function where carers were encouraged to send posts and comments. MOSTalso includes a forum-style, group problem-solving function, entitled ‘talk it out’, which was derived from multifamily therapy (Berkowitz & Gunderson, 2002).

Program moderation was provided by an expert moderator, a HYPE clinician (clinical psychologist, MJ), and a trained family peer support worker with lived experience of caring for a young person with mental ill health. The expert moderator logged on to Kindred at regular intervals with the goal of encouraging self-care, self-efficacy and positive coping by making comments on the newsfeed and sending direct messages to users. The peer moderator modelled use of the system and facilitated online interactions.Moderators also organised two Kindred face-to-face ‘meet ups’ held during the course of the intervention which were designed to address users’ questions and encourage increased online interaction within Kindred.

The moderators and researchers checked the Kindred system daily to monitor users’ safety and to instigate a safety algorithm if indicated (Lederman et al., 2014).

All clients received routine relationally-informed clinical care at HYPE, comprising psychologically-informed case management, general psychiatric care, and individual CAT where indicated. Routine care in HYPE may include face-to-face individual sessions with specialist family clinicians and/or family peer support workers.

2.6 *Discontinuation and withdrawal criteri*a

Carers were excluded from Kindred if they failed to comply with the terms of use. Carers and their young person would be withdrawn from the intervention and/or research assessments: (i) if they requested this; (ii) at the discretion of an investigator.

2.7 *Measures*

Acceptability of Kindred was measured via participation and was operationalised*a priori* asat least 50% of carer participants logging on at an average rate of more than once per fortnight. *Usability* of the Kindred system was based on carer responses to the 19-item Post-Study Usability Questionnaire (PSSUQ)(Lewis, 2002). The user's experience of Kindred was assessed via a semi-structured interview (Bargas-Avila &Hornbæk, 2011) that explored six themes: enjoyment using the application; usefulness/helpfulness in supporting carers; comparison to face-to-face therapeutic interventions; how actively carers participated; value of specific components.

Safety was defined *a priori* as (i) all carer participants reporting feeling adequately supported; (ii) no more than two participants being excluded from the system; (iii) no withdrawals from Kindred due to adverse impacts on the well-being of participants associated with the system; and (iv) no unlawful entries into Kindred.

Carers' appraisal of the *burden* of the disorder on the family was measured using the Experience of Care-giving Inventory (ECI) (Szmukler et al., 1996).

Carer*stress*over the preceding monthwas assessed with the Perceived Stress Scale (PSS) (Cohen &Williamson, 1987). The Kessler Psychological Distress Scale (K-10) was also used to measure non-specific psychological distress in carers(Kessler et al., 2002). Hair cortisol concentration was used as a *biomarker of stress* in carers(Van Uum et al., 2008) via long-term alterations in basal hypothalamic-pituitary-adrenal (HPA) axis activity (Davenport et al., 2006). Mean baseline HPA system activity during the last 3 months was measured by collecting a hair sample (3 cm long, approximately 0.5 cm in diameter) at baseline and follow-up. Analyses of cortisol in hair were performed according to the established protocol by (Davenport et al., 2006).

The level of *expressed emotion* in carers was assessed via the Family Questionnaire (FQ) (Wiedemann et al., 2002).

F*amilycommunication* and quality of the relationship of carers and their young person was measured by administering the Parent-Adolescent Communication (PAC) Scale to carers(Barnes & Olson, 1985).

Carers'*quality of life* was assessed with the 12-item Assessment of Quality of Life - 4 Dimensions (AQoL-4D) (Richardson et al., 2014).

Carer*health and disability* was measured with 12 of the self-report items (S1 to S12) of the World Health Organization Disability Assessment Schedule 2.0 (WHODAS 2.0).

Three items of the self-report Sheehan Disability Scale (SDS) were used to generate a total score reflecting measure *functional impairment* across three domains - work/school, social life and family life, for both the carers and young people (Sheehan et al., 1996).

Carers' *coping* was assessed with Coping Inventory for Stressful Situations – Situation-Specific Coping (CISS-SSC) (Endler& Parker, 1994).

Three items of the self-report Personality Disorder Knowledge Attitudes and Skills Questionnaire (PDKASQ) were adapted for carers and used to capture perceived *knowledge of personality disorders*(Davies et al., 2014).

The self-report Borderline Symptom List (BSL-23) was used to measure the perceived *severity of BPD* symptoms(Bohus et al., 2009)in the young person.

A questionnaire developed for the current study was used to gather feedback from the young people about whether they felt Kindred had any effect upon their carers.

Secondary outcomes of *stress, expressed emotion, perception of family communication, coping strategies* and*unpleasant affect*were also assessed repeatedly in daily life using ecological momentary assessment (EMA). EMA data were collected using a purpose-built EMA smartphone app called *SEMA2*(Harrison et al., 2017), which participants installed on their own iOS or Android smartphone.*SEMA2* was programmed to administer 8 EMA surveys per day for 7 days at baseline and again for 7 days at follow-up. EMA items were developed by adapting items from previous EMA studies or from global/retrospective questionnaires (see supporting information).

2.8*Statistical analyses*

Descriptive statistics were generated to determine whether a priori thresholds of acceptability and safety had been met. For the exploratory outcomes, paired sample *t* tests were conducted and Cohen’s d for repeated measures was calculated. The reliable change index (RCI), the standardized change score for each participant, was also calculated for each exploratory outcome, and the critical RCI was set at 1.96 (Christensen & Mendoza, 1986).

Of the 17 carers with EMA data, five completed fewer than 20% of scheduled SEMA surveys at either baseline or follow-up and were therefore excluded from analyses.Thus, analyses of EMA data were based on the remaining (*n* = 12)[2]carers, who responded to an average of 52% (*SD* = 24%) and 55% (*SD* = 28%) of scheduled EMA surveys during baseline and follow-up assessments, respectively. EMA data were analyzed using multilevel models to account for nesting of EMA surveys (level-1) within participants (level-2) using Mplus version 8.4. Bayesian estimation withdiffuse priors was used, implyingthat model estimates are asymptotically equivalent to those obtained using Maximum Likelihood (Schoot et al., 2014; Zyphur& Oswald, 2013).

3.Results

3.1. Participant flow

A total of 53 carers were considered for this trial; of these 5 declined consent, 20 carers consented, and 19 completed baseline and 17 carers enrolled in the intervention (Figure 1). As the young people were only contacted subsequent to consenting the carers, only 15 young people were approached for consent within the recruitment time-frame, with 10 consenting, 8 completing baseline and 6 completing the follow-up assessment (Figure 2).

(Insert Figure 1 and 2 around here)

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[2] This included data from one carer who provided EMA data only at baseline and one carer who provided EMA data only at follow-up. Missing data from were treated as missing at random in our analyses.

3.2 Participant characteristics

As depicted in Table 1, the carers were mostly middle-aged (M = 48.1 years (SD = 10.3)) and female (73.7%). Most carers were employed (73.7%) and were in a relationship (73.7%). The majority of carers were mothers (73.7%).

(Insert Table 1 around here)

The majority of the young people identified as female gender (62.5%; Table 2). Sixty percent of the young people had full-syndrome BPD. Seventy-five percent of the young people were receiving their first episode of care with HYPE.

(Insert Table 2 around here)

3.3 *Interventions*

During the intervention period carers logged on to Kindred at a mean rate of 2.6 times per fortnight and a mean total of 17.2 times each (Table 3). The most frequently completed individual therapy step was “asking with empathy” followed by “what is BPD” and “introduction to BPD”.

(Insert Table 3 around here)

During their episode of care with HYPE, the young people attended a mean of 24.3 sessions (SD = 9.0, Interquartile range = 15.8). No carers attended any sessions with the specialist HYPE family-work clinician.

3.4 Primary outcomes

The *acceptability* criterion of 50% of carers logging on at an average rate of more than once per fortnight was surpassed with 11 of the 17 enrolled carers (64.7%) meeting this criterion.

Fifteen carers completed the *usability* questionnaire (PSSUQ), with their overall mean score of 2.3 (SD=1.2), indicating satisfaction with the usability of Kindred. At interview, carers reported that Kindred was acceptable as 66.7% (10/15) said that the intervention was enjoyable, 86.7% (13/15) were able to identify a component that they liked the most, and 66.7% (10/15) informed that they liked sharing information on the site.

In relation to *safety* outcomes, all the carers who provided feedback via the User Experience interviews (12/15) reported feeling adequately supported by the Kindred moderators. Two carers had not logged onto the system, so did not comment, and one carer preferred not to comment because they had used the system infrequently. No carers were excluded or withdrawn and there were no unlawful entries to the system.

3.5 Secondary outcomes

In relation to carer outcomes, the mean scores for experiences of burden, stress, expressed emotion, family communication, quality of life, functioning, coping, and perceived knowledge of BPD all improved between baseline to follow-up. Statistically significant differences were detected for a reduction in burden with more than half showing a reliable improvement (i.e. the negative experiences of caregiving) and the emotional overinvolvement component of expressed emotion with 50% showing a reliable improvement (Table 4). A large effect size was identified for hair cortisol (Cohen's d_{RM}=-1.41) with 43% showing a reliable improvement and medium effect sizes for emotional overinvolvement (Cohen's d_{RM}=-0.67), both negative and positive experience of caregiving (Cohen's d_{RM}=-0.59 and 0.57 respectively), critical comments (Cohen's d_{RM}=-0.63; 57% reliable improvement), and family communication (Cohen's d_{RM}=0.64; 33% reliable improvement). Small to medium effects were achieved for other secondary outcomes.

(Insert Table 4 around here)

Multilevel reliability analyses (see Geldhof, Preacher &Zyphur, 2014) revealed that the four items used to assess Perceptions of Family Communication (ω_{within}= .57,ω_{between}=.86) and the nine items used to assess Unpleasant Affect (ω_{within}= .88,ω_{between}=.98)formed quite reliable scales. However, the two items assessing Expressed Emotion were uncorrelated within persons (r_{within}= .05) and correlated positively (rather than negatively, as expected) between persons (r_{between}=.61). Thus, we analysed the two Expressed Emotion items separately. Coping strategies were also treated as separate outcomes.

In the relation to the EMA variables, fixed effect estimates of the interceptsand change slopes generated from the multi-level models are reported in Table 5. The point estimates for change slopes were mostly in the expected direction, however, we found no evidence of reliable change in any of the EMA outcomes from baseline to follow-up.

(insert Table 5 around here)

In relation to the outcomes for the young people, at baseline the young people (n=6) had a mean of 2.0 (SD=0.9) for BPD severity and at follow-up this had reduced to a mean of 1.5 (SD=0.6) with 33% reliable improvement and 0% reliably worse scores, which was not statistically significant change (p=0.194). At baseline, the young people's (n=5) mean global functioning score was 17.4 (SD=7.5) and at follow-up it had improved to 11.0 (SD=2.9) with 60% reliably improved scores and 0% reliably worse scores, although again, this change was not statistically significant (*p*=0.075). The magnitude of change was medium for BPD severity (Cohen’s $d_{RM}=-0.54$, 95% confidence intervals -1.7 to 0.61) but large for functional impairment (Cohen’s $d_{RM}=-1.047$, 95% confidence intervals -2.37 to 0.28).

Sixty-six percent of the young people (4/6) reported that they believed Kindred had improved their carers’ understanding of BPD. Sixty-six percent (4/6) also reported that Kindred had a positive effect on their interactions with their carers.

4. Discussion

This is the first trial to report outcomes for an interactive online social media-based intervention for carers of young people with BPD features. Kindred was developed to address issues with our previous BPD carer interventions, namely, to increase the “dose”, to improve the adherence to the intervention, and to examine changes in burden, knowledge of BPD, family communication patterns, and stress and coping.

The current sample of carers was very similar to the sample recruited to the pre-post MS-BPD study in terms of mean age and mean level of psychological distress at baseline (Pearce et al., 2017). The mean distress score conveyed approximately a 55% probability of an ICD-10 mental health disorder in the preceding 12 months (Andrews & Slade, 2001). We also note that in comparison with the sample of carers of adolescents and adults with BPD (aged ≥14 years) recruited by Grenyer and colleagues (Grenyer et al., 2019), the current sample of carers reported slightly lower levels of criticism and higher levels of emotional over-involvement, which might reflect changes in carer patterns across developmental phases.

This 3-month pilot of Kindred provided promising data in terms of both acceptability and safety in line with our multiple *a priori* criteria. Acceptability and engagement with online interventions has been a significant challenge in mental health applications (Eysenbach, 2005). We suspect that the proactive approach taken by Kindred moderators to monitoring and prompting participants was important in achieving these outcomes. The follow-up data indicated that Kindred, in addition to receipt of services at HYPE, was associated with statistically significant reductions in carer burden, and expressed emotion. There was also evidence for improvement in stress, communication, quality of life, coping and knowledge of personality disorders. These improvements occurred even though no carers attended a session with the specialist HYPE family-work clinician.

The findings from the carer self-report measures were consistent with the reduction in hair cortisol at 3 months. To the best of our knowledge, this is the first such study to utilize this measure in a mental health carer population (Staufenbiel et al., 2013).

This pattern of improvement in carers appears roughly congruent with the take-up of therapy content - participants most frequently accessed psychoeducational content related to BPD and communication styles, which would be expected to improve BPD knowledge, expressed emotion and family communication.

We did not find evidence of meaningful change between baseline and follow-up in the EMAmeasures, although estimates were in the expected direction for most outcomes. This suggests that there are differences between carers'momentary experience and their recall of recent stress, expressed emotion, communication and unpleasant affect (Coner& Barrett, 2012; Kahneman, 2011).

In relation to the young person characteristics, the BSL-23 scores corresponded very closely with the the BSL-23 validation study (*n*=379) (Bohus et al., 2009), indicating that the symptom severity of the current sample was comparable with adult patients with BPD.

4.1 Strengths and limitations

We set robust *a priori* criteria for our primary outcomes of acceptability, usability and safety using a variety of measurement methods. In addition, we measuredcarer outcomes using a variety of measurement methods including a promising approach to the objective measurement of change in chronic stress, namely, hair cortisol.

As a pilot study, the sample size was small and thus the study was underpowered for significance testing on some outcomes, most notably for outcomes administered via SEMA. Whilst the rate of refusal was low, the major constraint on our capacity to recruita greater proportionof the available participants was the total RA resources available forthis pilot scale study. Full-scaled RCTs that involve recruiting from this population need to be resourced such that all available carers have an opportunity to provide consent.

Whilst acceptability was encouraging, carers engaged less with content that was designed to improve carer well-being in preference to content that would improve their understanding and relationship with the young person. In further iterations of Kindred more overt links could be made between self-care and the benefits for the young person, e.g., that parents who invest in self-care such as mindfulnessare more likely to respond with greater psychological flexibility which has been shown to be beneficial to their children(Leeming & Hayes, 2016). However, the participation findings in the current pilot compare favourably with the typical rate of 50% adherence to health-related web-based interventions (Kelders et al., 2012).

Just over half of the EMA surveys were completed at each time point by the subset of participants who provided consent for this additional component of the study which in hindsight is not surprising given the high number of daily surveys requested. In future EMAinvestigations with this population the optimal frequency and timing of daily surveys should be more appropriately tailored for participantsand a reimbursement schedule specifically for EMA survey completion should be incorporated into the procedure.

Given the study design, we cannot isolate Kindred as the cause of improvements. However, change in carer outcomes can also not be attributed to face-to-face family work at HYPE because no carers availed themselves of this service. It is also possible that the variety of improvements resulted from changes in a single domain, e.g., increased understanding via non-blaming psychoeducation.

Given the acceptability, usability, safety outcomes and the encouraging changes over time in both carer and young person outcomes, the question of the efficacy of Kindred now warrants evaluation via an RCT. Certainly the integration of digital technology into mental health care for the support of carers is in its infancy, and this pilot study provides a tangible step forward to providing accessible and effective support for these highly burdened families.

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Conflict of Interest Statement

There are no competing interests to report.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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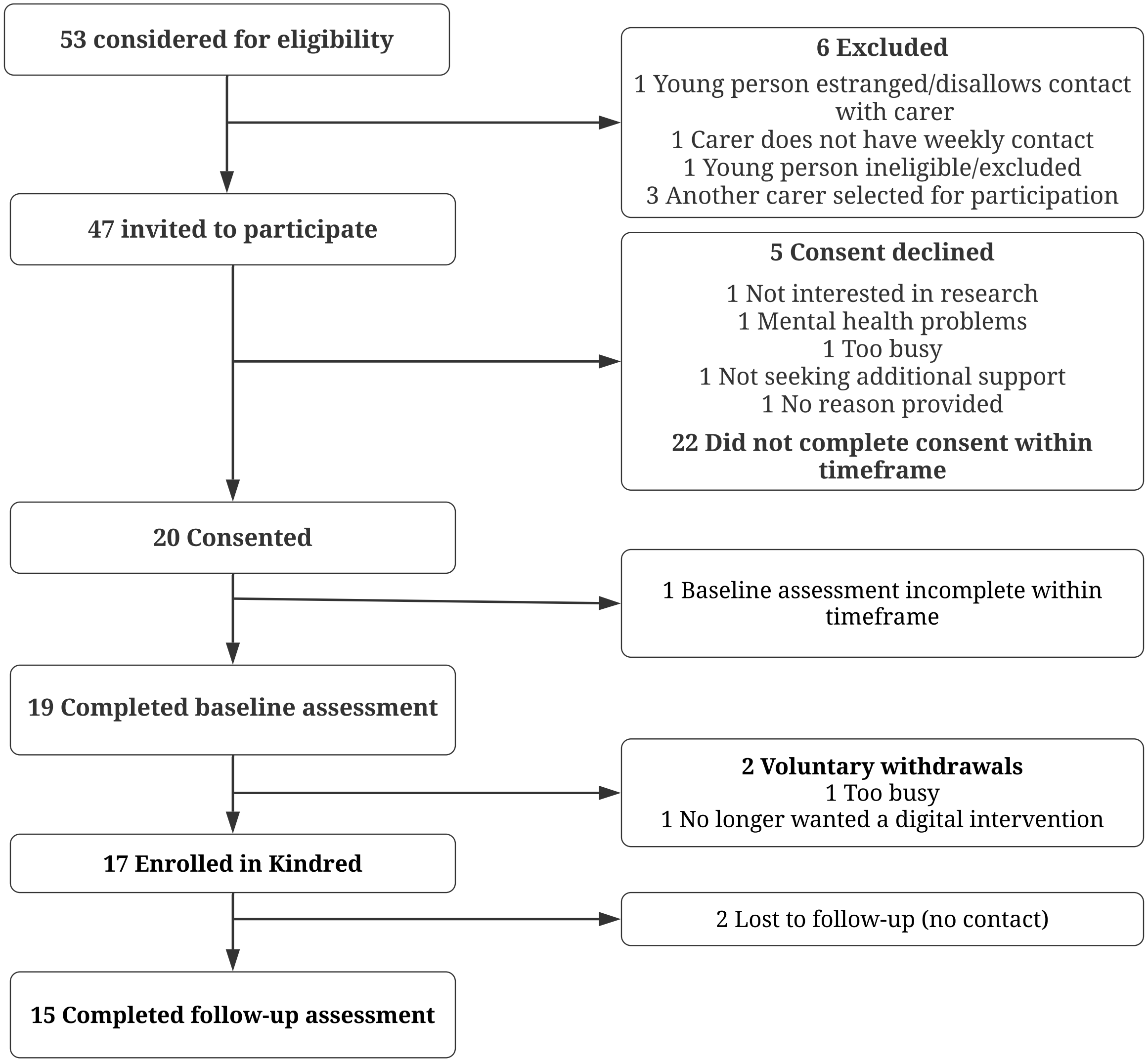

Figure 1 Carer consort

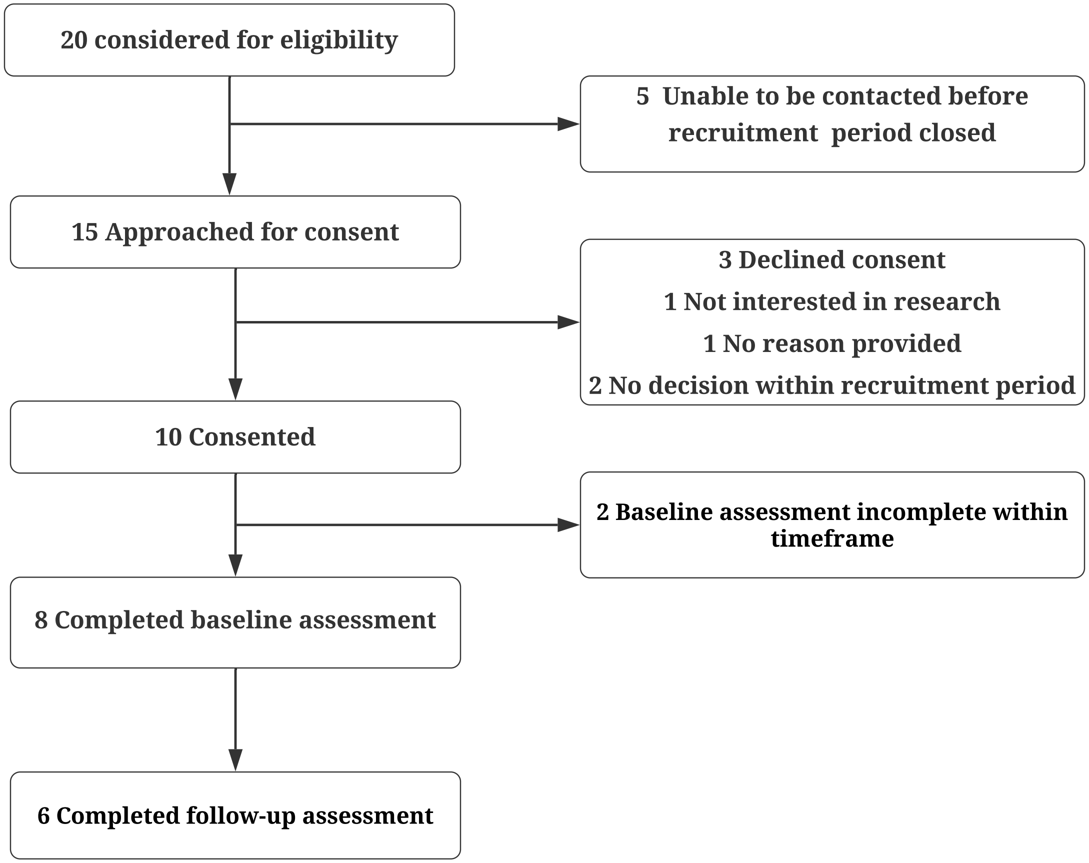

Figure 2 Young person consort

Table 1 Demographic characteristics of the carer participants

Characteristics	Descriptive statistic	Total sample *N*=19
Age (years)	*M(SD)*	48.1 (10.3)
	Range	23-61
Sex assigned at birth and current gender identity (%Female)	%(n)	73.7 (14)
Relationship with young person		
Mother	%(n)	73.7 (14)
Father	%(n)	10.5 (2)
Partner	%(n)	10.5 (2)
Uncle	%(n)	5.3 (1)
Highest level of education completed		
Secondary-school level	%(n)	42.1 (8)
University-level	%(n)	42.2 (8)
Trade	%(n)	15.8 (3)
Employment status		
Full-time	%(n)	31.6 (6)
Part-time	%(n)	26.3 (5)
Unemployed	%(n)	21.1 (4)
Casual work	%(n)	15.7 (3)
Homemaker	%(n)	5.3 (1)
Marital status		
Married / de facto for > 2 years	%(n)	68.4 (13)
Separated / divorced	%(n)	21.1 (4)

Partner	%(n)	5.3 (1)
Single	%(n)	5.3 (1)
Main source of income †		
Employment	%(n)	82.4 (14)
Personal savings	%(n)	11.8 (2)
Disability payment	%(n)	5.9 (1)

† *N=17*

Table 2 Demographic and clinical characteristics of the young people participants

Characteristics	Descriptive statistic	Total sample
		N=8
Age		
	M(SD)	18.9 (3.2)
	Range	16-25
Sex assigned at birth (%Female)	%(n)	87.5 (7)
Gender identity		
Male	%(n)	12.5 (1)
Female	%(n)	75.0 (6)
Gender-queer/gender non-conforming	%(n)	12.5 (1)
Highest level of education completed		
Secondary school (Year 7-10)	%(n)	25.0 (2)
Secondary school (Year 11-12)	%(n)	62.5 (5)
University level	%(n)	12.5 (1)
Current study		
Not currently studying	%(n)	37.5 (3)
Secondary school	%(n)	37.5 (3)
University	%(n)	12.5 (1)
Online course	%(n)	12.5 (1)
Current work status		
Unemployed	%(n)	62.5 (5)
Casual work	%(n)	37.5 (3)
Marital status		
Single	%(n)	87.5 (7)
Married / de facto for more than 2 years	%(n)	12.5 (1)

Main source of income		
Parents	%(n)	50.0 (4)
Casual employment	%(n)	25.0 (2)
Government benefits (Youth Allowance)	%(n)	25.0 (2)
Mental State Diagnoses[†]		
Any mood	% (n)	80.0 (8)
Any anxiety disorder	% (n)	60.0 (6)
Any substance use disorder	% (n)	50.0 (5)
Any eating disorder	% (n)	10.0 (1)
Any somatoform disorder	% (n)	10.0 (1)
No diagnoses	% (n)	0 (0)
Number of current diagnoses	M (SD)	2.75 (1.0)
BPD pathology		
Number of criteria met	M (SD)	4.4 (1.3)
BPD diagnosis (≥5 criteria)	% (n)	62.5 (5)

BPD=borderline personality disorder. †Categories not mutually exclusive;

Table 3 Patterns of use of the Kindred intervention (n=17)

Intervention component	Total	Mean	Standard deviation	Median	Interquartile range
Log ons	292	17.2	15.6	13	28.5
Posts	105	6.2	9.9	3	6
Unique therapy modules completed (steps)	179	10.5	11.5	6	16
Total therapy modules completed (steps)	248	14.6	20.3	6	21.5

Table 4 Change in carer outcomes between baseline and 12-week follow-up (n=15)

Outcome	Baseline *M (SD)*	Follow-up *M (SD)*	P value	Cohen's d_{RM}	95% CI d_{RM} Lower	95% CI d_{RM} Upper	n (%) > $RCI_{critical}$	n (%) < $RCI_{critical}$	
Burden									
Positive caregiving experiences[†]	29.6 (5.0)	32.6 (7.8)	0.141	0.57	-0.19	1.32	6 (43)	2(14)	
Negative caregiving experiences[†]	123.1 (36.7)	109.7 (36.2)	0.045	-0.59	-1.35	0.17	8(57)	1(7)	
Stress									
Perceived stress	21.2 (5.4)	20.1 (5.4)	0.396	-0.23	-0.95	0.49	8(53)	5(33)	
Psychological distress	21.6 (9.1)	20.8 (7.3)	0.642	-0.11	-0.83	0.6	4(27)	4(27)	
Biomarker of stress (hair cortisol (ng/50mg))[‡]	1.4 (1.3)	0.8 (0.6)	0.062	-1.41	-2.575	-0.235	3(43)	0(0)	38% (3/8)
Expressed emotion									
Critial comments[†]	26.7 (6.2)	24.9 (6.9)	0.051	-0.63	-1.39	0.13	8(57)	2(14)	
Emotional overinvolvement[†]	30.7 (6.9)	28.4 (5.4)	0.046	-0.67	-1.43	0.1	7(50)	2(14)	
Family communication	57.1 (12.3)	65.0 (16.4)	0.058	0.64	-0.09	1.38	5(33)	2(13)	
Quality of life	0.64 (0.2)	0.71 (0.2)	0.252	0.23	-0.43	1.01	5(33)	3(20)	
Health and disability	6.2 (7.0)	6.1 (7.6)	0.931	-0.2	-0.74	0.69	3(20)	2(13)	
Functional impairment	8.9 (8.8)	6.4 (8.2)	0.091	-0.46	-1.18	0.27	3(20)	3(20)	
Coping behaviour									
Task-oriented coping (T-score)[†]	50.3 (11.3)	50.1 (11.3)	1	-0.09	-0.83	0.65	5(36)	4(29)	
Emotion-oriented coping (T-score)[†]	53.6 (13.2)	52.5 (11.0)	0.734	0	-0.74	0.74	4(29)	3(21)	
Avoidance-oriented coping (T-score)[†]	46.1 (9.4)	42.4 (8.8)	0.26	-0.3	-1.05	0.44	10(71)	2(14)	
Personality disorder knowledge	3.0 (1.2)	3.6 (0.7)	0.062	0.46	-0.27	1.19	8(53)	2(13)	

M=mean; SD=standard deviation; $_{RM}$=repeated measures; CI=confidence interval; PSS=Perceived Stress Scale; FQ=Family Questionnaire; ECI=Experience of Caregiving Inventory; †n=14; PACS=Parent-Adolescent Communication Scale; PD-KASQ=Personality Disorders-Knowledge, Attitudes and Skills Questionnaire; AQoL-4D=Assessment of Quality of Life-Four Dimensions; WHODAS=World Health Organisation Disability Assessment Schedule; SDS=Sheehan Disability Scale; CISS:SSC=Coping Inventory for Stressful Situations: Situation Specific Coping; K10=Kessler 10-question scale. ‡n=8, ng= nanogram mg=milligram. n(%) > RCI$_{critica}$l = n(%) reliably improved scores from baseline to 3 months; n(%) < RCI$_{critical}$ = n(%) reliably worse scores at 3 months.

Table 5. Mean levels and change slopes for EMA outcomes from baseline to follow-up

	Intercept (mean level)			Change Slope (follow-up vs. baseline)		
		95% CI			95% CI	
EMA outcome	Estimate	LL	UL	Estimate	LL	UL
Stress	19.80	3.42	35.28	–3.17	–18.63	11.87
Expressed emotion						
Item 1 (felt frustrated)	2.34	0.41	4.17	–0.24	–2.52	2.22
Item 2 (helpful solutions)	20.13	9.00	31.72	2.93	–11.40	17.92
Perception of family communication	56.73	43.20	70.37	–4.09	–20.72	13.44
Coping strategies						
Optimism	52.88	28.96	76.43	8.65	–17.02	33.24
Support seeking	12.04	–0.38	24.89	1.21	–5.16	7.28
Avoidance	39.83	24.40	53.97	2.49	–9.99	14.66
Worry	27.17	13.24	40.07	–4.58	–25.56	16.87
Unpleasant affect	14.44	6.78	22.61	–1.57	–9.63	6.26

Note. All models used data from *n* = 12 participants.
95% CI = 95% Bayesian credible interval.