

Living Well on Haemodialysis: feasibility and acceptability trial of an online Acceptance and Commitment Therapy (ACT) programme for people receiving kidney haemodialysis

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Abstract

Background: People receiving kidney haemodialysis need psychological support.

Objectives: To assess feasibility and acceptability of a 4-week online video-based Acceptance and Commitment Therapy (ACT) programme for people receiving kidney haemodialysis.

Design: Single group before-and-after study.

Participants: People with end-stage kidney disease currently receiving dialysis, who had received in-centre haemodialysis at least 90 days in the last two years.

Measures: Recruitment, retention and engagement (feasibility); weekly and post-programme feedback (acceptability); pre-intervention and 4-week follow-up (potential outcomes measures): kidney disease quality of life (KDQOL-SF), psychological flexibility (Acceptance and Action Scale) and acceptance of illness (Acceptance of Illness Scale).

Results: The study recruited 13 participants of whom 85% completed at least half the programme and 69% completed the whole programme. Health and medical treatment issues were the main known reasons for non-participation and drop-out. Of the 16 separate elements of the programme (four 'story' videos and 12 videos explaining ACT techniques), 13 were positively evaluated by at least 75% of participants. Of 11 aspects of the programme, 8 were positively evaluated by at least 75% of participants, and 89% found the programme easy to use, understood how it worked, found it easy to access, trusted the information, had no technical difficulties, and understood the activities. However, only 66.7% agreed the programme was interesting and only 62.5% agreed they enjoyed the programme. All responding participants indicated they would recommend the programme to people starting dialysis. The direction of change was positive for 17/21 potential outcome measures, with significant ($p < 0.05$) improvements in psychological flexibility and energy/fatigue.

Conclusions: An online video-based ACT intervention was feasible and acceptable for people receiving kidney haemodialysis and the results provide pilot data for a planned larger trial.

Key words: Acceptance and Commitment Therapy; haemodialysis; feasibility; acceptability

Introduction

Over 24,000 people with kidney failure in the UK receive in-centre haemodialysis (at a hospital or satellite clinic) and 1,400 receive home haemodialysis (UK Renal Registry, 2021). Haemodialysis involves blood filtration via dialysis machine, usually for four hours per treatment, three times per week, which extends life but causes significant cardiovascular morbidity (Foley et al., 1998), reduced quality of life (Cukor et al., 2007; Fukuhara et al., 2003; Viramontes-Hörner et al., 2022), and increased risk of depression and psychological distress (Fischer et al., 2021; Palmer et al., 2013).

Acceptance and commitment therapy (ACT) is a mindfulness-based behavioural therapy to help people lead rich, meaningful lives despite distressing or challenging circumstances (Harris, 2006). ACT has helped people with long-term medical conditions to improve their resilience and adjustment (Gloster et al., 2020; Graham et al., 2016). Reaching acceptance and building emotional resilience were both features of successful psychosocial adjustment among people receiving long-term in-centre haemodialysis (Kapadi et al., 2023) and ACT

could help people receiving dialysis to achieve those things (Rzeszut, 2011; Stalker et al., 2018). Online, self-directed ACT programmes can be effective (Klimczak et al., 2023), and flexible, scalable psychosocial support for haemodialysis patients is needed to supplement limited in-person psychosocial support (Seekles et al., 2019). This paper describes preliminary evaluation of an ACT-based programme that could potentially help to meet that need. The aims were to:

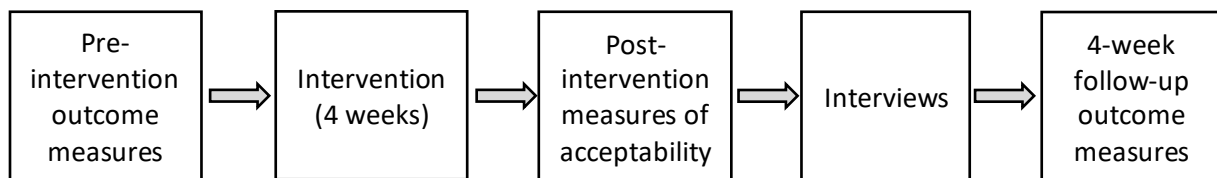
1. Assess the feasibility of recruiting, retaining and engaging participants.
2. Assess how acceptable participants found the programme.
3. Assess the feasibility and acceptability of potential outcome measures.
4. Explore participants' experiences of the programme.

Methods

A single-group feasibility and acceptability study with pre-intervention and follow-up to pilot potential outcome measures (see Figure 1). The study protocol was approved by the College of Health, Psychology and Social Care research ethics committee (Ref. 2122-0671).

Recruitment and pre-intervention data collection took place between November 2021 and January 2022 and the programme was delivered during January and February 2022. Post-programme interviews were conducted in March 2022, and follow-up data were collected during March and April 2022. The trial was registered with the ISRCTN Registry (No. 10070371) in February 2022, before any of the evaluation data were collected.

Figure 1. Study flow



Participants

The participants were 13 people who were aged over 18 years, had received in-centre haemodialysis for at least 90 days in the last two years, and were able to converse in English. People unable to use the intervention because of a medical complication or unable to use an online programme were excluded.

The intervention

'Living Well on Haemodialysis' is a 4-week programme of 19 short films using Toonly®, comprising four 'story' films (with fictional patients represented by cartoon figures and scripted audio recorded by real dialysis patients) and 12 'explainer' films (short presentations of ACT techniques with audio recorded by a qualified ACT therapist), plus introduction and overview films at the beginning and end, and an Urgent Help film with signposting to sources of human support (see Figure 2). People with experience of haemodialysis contributed to the programme development (Elander et al., 2021) and the

programme was directed by an ACT-trained clinical psychologist and delivered online, with materials released weekly and previously released materials remaining accessible.

Procedure

Invitations to participate were posted online by the Kidney Patient Involvement Network, Kidney Research UK, the National Kidney Federation, Kidney Care UK, the UK Renal Registry and the UK Kidney Association. Invitations directed people to the project website for more information and to confirm eligibility and informed consent. Eligible, consenting participants completed pre-intervention measures and were emailed individually with links to each week's materials.

Post-programme interviews via Microsoft Teams with participants about their experiences of the programme covered first impressions, impressions of the videos, most and least helpful aspects, suggestions for improvements, frequency of viewing, and video-text balance. Four weeks post-programme, participants were emailed a link to the follow-up questionnaire. Participants who completed at least two weeks of the programme received a £30 shopping voucher to recognise their time and effort.

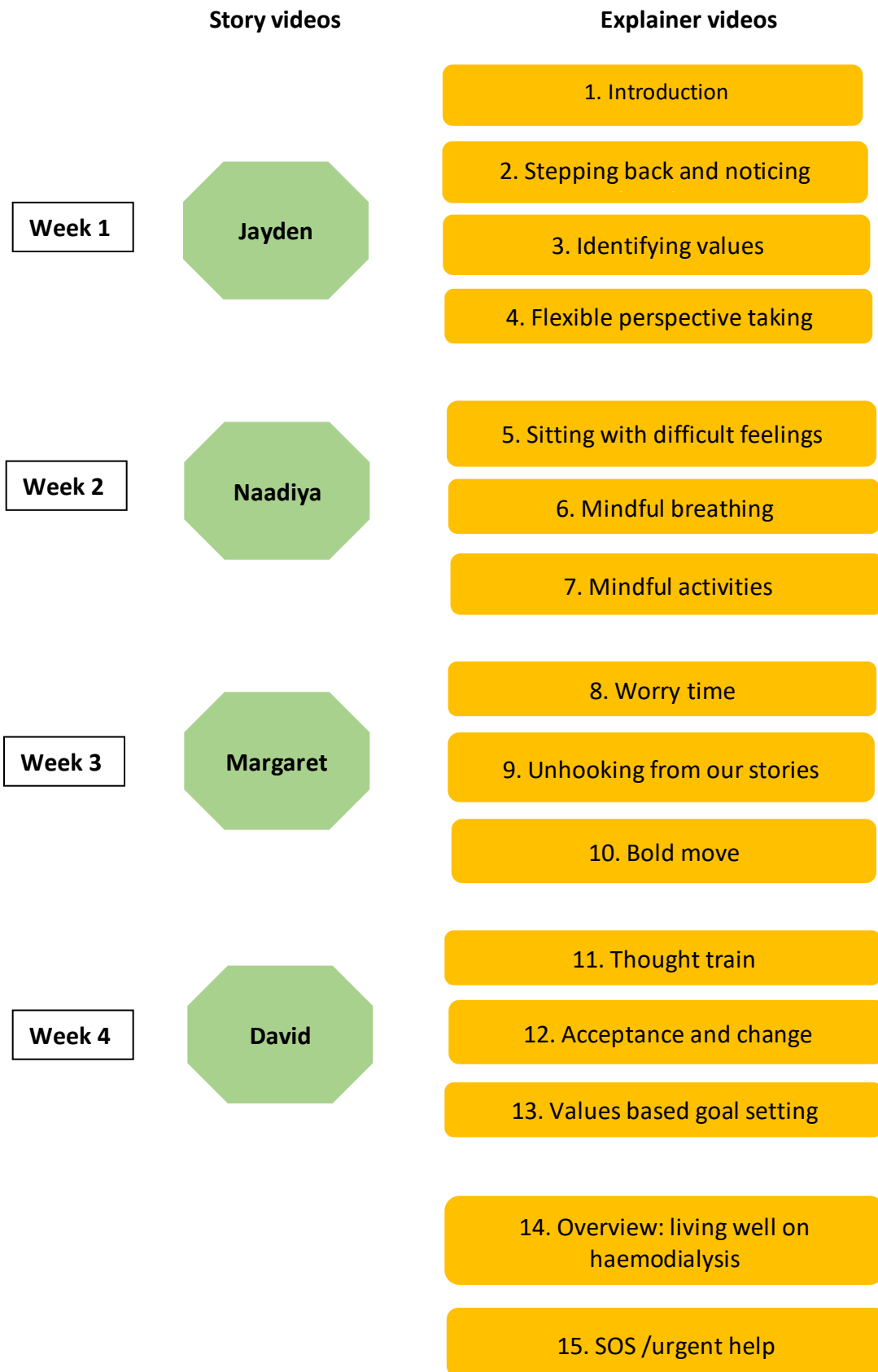
Measures

Feasibility was assessed by recording recruitment, retention, weekly engagement, use of activities and adverse events. Acceptability was assessed by weekly and post-intervention feedback. Each week, participants rated how realistic the story was, how useful the explainer films were, and how useful that week's content would be to someone new to dialysis (5-point scales: 'not at all', 'slightly', 'moderately', 'very', 'extremely').

Post-intervention, participants indicated how often they used each of the activities and rated agreement with statements about the programme (5-point scales: 'strongly disagree' to 'strongly agree'). They also indicated how likely they would be to use the programme again and recommend it to people starting dialysis (5-point scales: 'definitely not' to 'definitely would'). Participants also indicated how they felt about completing the programme without a professional to talk to, and, having completed the programme, how likely they would be to look for psychological support. Three free-text questions asked: 'what were the best things about the programme?', 'how could it be improved?', and 'any other comments about the programme or how it affected you?'.

At pre-intervention and follow-up, participants completed the Kidney Disease Quality of Life Short Form (KDQOLSF) (Hays et al., 1997), the Acceptance and Action Scale, which measures psychological flexibility (AAS; Bond et al., 2011), and the Acceptance of Illness Scale (AIS; Felton et al., 1984). The KDQOLSF is a widely used condition-specific outcome measure, and the AAS and AIS measure psychological processes relevant to ACT.

Figure 2. Programme structure



Data analysis

Feasibility was defined as: 1) recruiting at least 10 participants and recruiting 75% of those eligible over 3 months; 2) at least 80% retention; 3) at least 75% of participants engaged each week and using each activity; 4) no serious adverse events. Acceptability was defined as positive evaluations ('very' or 'extremely', and 'agree' or 'strongly agree') by at least 75% of participants. Feasibility and acceptability of outcome measures was defined as completion of scales with less than 10% missing data and indications they were viable before-and-after measures of change.

The recruitment target was low to enable the researchers to communicate with participants individually. Other targets were based on previous trials of behavioural interventions for people receiving dialysis and ACT interventions for long-term conditions, plus CONSORT guideline examples. A feasibility trial of an intervention for people receiving haemodialysis had targets of 75% recruitment and 80% retention (Carswell et al., 2020). In a trial of ACT for chronic fatigue, 80% completed the programme and 66.7% reported they would recommend it (Jonsson et al., 2019). CONSORT guideline examples had targets of 70% for participating in workshops, 65% for mean satisfaction with workshops, and less than 10% for missing questionnaire data (Eldridge et al., 2016).

Changes from pre-intervention to follow-up were tested with Wilcoxon signed-rank tests. Interviews were recorded and verbatim transcripts analysed using descriptive thematic analysis (Braun & Clarke, 2006).

Results

Feasibility

Recruitment and participants

Twenty-two people expressed interest, of whom 20 were eligible. Of those, 13 (65%) consented and completed pre-intervention measures (Figure 3). People who expressed interest earlier and had to wait to begin the programme were less likely to participate. Health issues were the main known reasons for non-participation.

There were nine female and four male participants. Ages ranged from 20 to 64 years. Two participants had non-white ethnic identities. Nine were married or cohabiting; nine had children; only three were working. Participants had been on dialysis between one and 14 years. Nine presently received in-centre haemodialysis and four presently received home haemodialysis, although all met the inclusion criterion of having received in-centre haemodialysis for at least 90 days in the last two years. Nine had co-morbid conditions, including diabetes, high blood pressure and arthritis (Table 1).

Retention and engagement

Of 13 participants, one dropped out before starting and one dropped out after week 1. Eleven participants (85%) were retained for at least two weeks, including one who completed only weeks 1, 2 and 4, and one who completed only weeks 2 and 3. Nine participants (69%) were retained for all four weeks and follow-up (Figure 3).

Engagement was 85% (11/13) for weeks 1 and 2 and 77% (10/13) for weeks 3 and 4. In weeks 2 and 4 there was one participant who engaged with the programme but did not provide weekly feedback. Health issues were the main known reasons for non-engagement. Overall activity use reported by participants who completed the post-programme survey was 94.4% (102/108).¹ Many participants used activities multiple times, especially *sitting with difficult feelings, mindful breathing, and worry time* (Full engagement data is available from <https://www.isrctn.com/ISRCTN10070371>).

Adverse events

No participants reported adverse events; the only difficulty involved a technical issue experienced when viewing the programme via a tablet.

Figure 3. Study flowchart

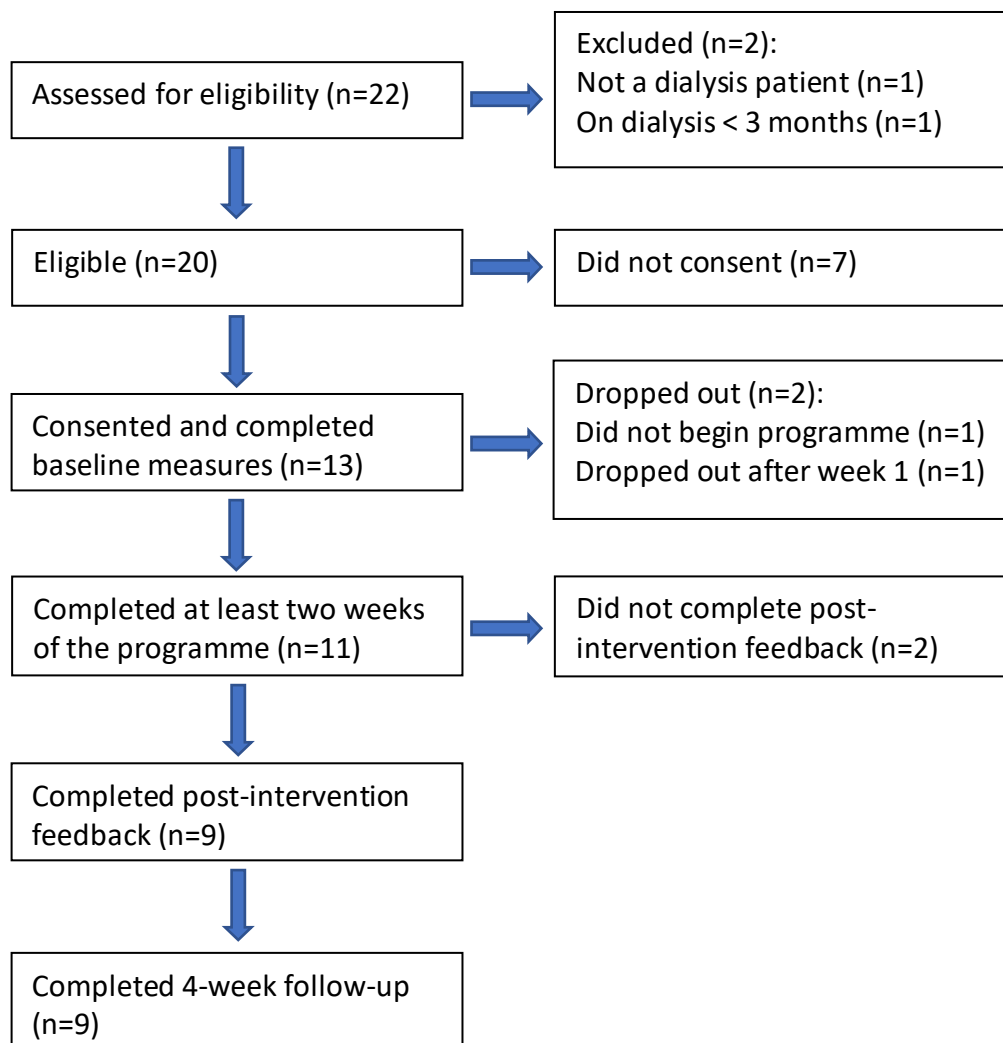


Table 1. Participant characteristics¹

| Pseudonym | Age | Gender | Cohabiting ² | Children | Ethnic identity | Working ³ | Type of current dialysis ⁴ | Years on dialysis | Co-morbidities | Region |
|--------------|-----|--------|-------------------------|----------|-----------------|----------------------|---------------------------------------|-------------------|----------------|--------------------|
| 1. Polly | 40s | Female | Yes | Yes | White | No | ICHD | 1 | Yes | Greater London |
| 2. Karen | 60s | Female | Yes | Yes | White | No | ICHD | 4 | No | Midlands |
| 3. Susan | 40s | Female | No | Yes | White | No | ICHD | 1 | Yes | Scotland |
| 4. Keith | 20s | Male | No | No | White | No | HHD | 2 | Yes | Midlands |
| 5. Joan | 50s | Female | Yes | Yes | White | No | HHD | 1 | Yes | North-West England |
| 6. Tracey | 40s | Female | Yes | No | White | No | ICHD | 1 | Yes | Midlands |
| 7. Carol | 50s | Female | Yes | No | White | No | ICHD | 2 | No | South-East England |
| 8. Elizabeth | 60s | Female | Yes | Yes | White | No | ICHD | 1 | Yes | South-East England |
| 9. Kaur | 50s | Male | No | Yes | Asian | Yes | ICHD | 1 | No | South-East England |
| 10. John | 50s | Male | No | No | White | Yes | ICHD | 2 | Yes | North-West England |
| 11. Peter | 50s | Male | Yes | Yes | White | Yes | HHD | 1 | No | South-West England |
| 12. Sophie | 60s | Female | Yes | Yes | White | No | ICHD | 5 | Yes | South-West England |
| 13. June | 50s | Female | Yes | Yes | Black | No | HHD | 14 | Yes | Greater London |

Notes:

1. Some details have been changed to protect participants' anonymity.
2. Yes=married, civil partnership or cohabiting; no=single, divorced or separated.
3. Yes=full-time or part-time; no=retired or not working because of illness.
4. ICHD=in-centre haemodialysis; HHD=home haemodialysis.

Acceptability

Weekly ratings for realism of story films, usefulness of explainer films, and usefulness of each week's content for someone new to dialysis are given in Tables 2–4. The proportions of participants who rated story films as very or extremely realistic were above 75% for all four stories (Table 2). The proportions who rated explainer films as 'very useful' or 'extremely useful' were above 75% for 9/12 films, the exceptions being *identifying values* (63.6% 'very useful' or 'extremely useful'), *flexible perspective-taking* (63.6%), and *mindful breathing* (70%) (Table 3). The proportions who rated each week's content as very or extremely useful for someone new to dialysis were above 75% for all four weeks (Table 4).

Table 2. Weekly ratings of how realistic the difficulties portrayed in the stories were.

| | Not at all | Slightly | Moderately | Very | Extremely |
|-----------------|------------|----------|------------|-----------|-----------|
| Jayden (n=11) | 0 | 0 | 2 (18.2%) | 5 (45.5%) | 4 (36.4%) |
| Naadiya (n=10) | 0 | 0 | 0 | 7 (70%) | 3 (30%) |
| Margaret (n=10) | 0 | 0 | 2 (20%) | 4 (40%) | 4 (40%) |
| David (n=9) | 0 | 0 | 1 (11.1%) | 3 (33.3%) | 5 (55.6%) |

Table 3. Weekly ratings of how useful the explainer films were.

| | Not at all | Slightly | Moderately | Very | Extremely |
|-------------------------------------|------------|-----------|------------|-----------|-----------|
| <i>Week 1 (n=11)</i> | | | | | |
| Stepping back and noticing thoughts | 0 | 0 | 2 (18.2%) | 6 (54.5%) | 3 (27.3%) |
| Identifying values | 0 | 2 (18.2%) | 2 (18.2%) | 3 (27.3%) | 4 (36.4%) |
| Flexible perspective taking | 0 | 0 | 4 (36.4%) | 4 (36.4%) | 3 (27.3%) |
| <i>Week 2 (n=10)</i> | | | | | |
| Sitting with difficult feelings | 0 | 0 | 1 (10%) | 6 (60%) | 3 (30%) |
| Mindful breathing | 0 | 0 | 3 (30%) | 2 (20%) | 5 (50%) |
| Mindful activities | 0 | 0 | 1 (10%) | 5 (50%) | 4 (40%) |
| <i>Week 3 (n=10)</i> | | | | | |
| Worry time | 0 | 0 | 2 (20%) | 4 (40%) | 4 (40%) |
| Unhooking from thoughts | 0 | 0 | 1 (10%) | 6 (60%) | 3 (30%) |
| Bold move | 0 | 0 | 0 | 5 (50%) | 5 (50%) |
| <i>Week 4 (n=9)</i> | | | | | |
| Thought train | 1 (11.1%) | 0 | 1 (11.1%) | 4 (44.4%) | 3 (33.3%) |
| Acceptance and change | 0 | 0 | 0 | 6 (66.7%) | 3 (33.3%) |
| Values-based goals | 0 | 1 (11.1%) | 0 | 6 (66.7%) | 2 (22.2%) |

Table 4. Weekly ratings of how useful each week's content would be for someone new to dialysis.

| | Not at all | Slightly | Moderately | Very | Extremely |
|---------------|------------|----------|------------|-----------|-----------|
| Week 1 (n=11) | 0 | 0 | 2 (18.2%) | 5 (45.5%) | 4 (36.4%) |
| Week 2 (n=10) | 0 | 0 | 0 | 5 (50%) | 5 (50%) |
| Week 3 (n=10) | 0 | 0 | 0 | 6 (60%) | 4 (40%) |
| Week 4 (n=9) | 0 | 0 | 0 | 5 (55.6%) | 4 (44.4%) |

In post-programme ratings, the proportions of participants who agreed/strongly agreed were above 75% for 8/11 statements, and 8/9 participants (88.9%) agreed/strongly agreed they found the programme easy to use, understood how it worked, found it easy to access, trusted the information, had no technical difficulties, and understood the activities (statements 1, 2, 3, 7, 8 & 11). However, only 6/9 (66.7%) agreed/strongly agreed the programme was interesting and would help them live better on dialysis and 5/8 (62.5%) agreed/strongly agreed they enjoyed the programme (statements 4, 5 & 6). Eight of nine probably/definitely would use the programme again and 9/9 probably/definitely would recommend it for people starting dialysis (Table 5). No one definitely missed being able to talk to a professional and participants had mixed views about looking for psychological support after the programme (Table 6).

Table 5. Post-programme ratings of agreement with statements about the programme.

| Statement | Strongly disagree | Disagree | Not sure | Agree | Strongly agree |
|---|-------------------|--------------|-----------|----------------|------------------|
| 1. It was easy to start using the materials | 0 | 1 (11.1%) | 0 | 2 (22.2%) | 6 (66.7%) |
| 2. I understood how the programme worked | 0 | 1 (11.1%) | 0 | 3 (33.3%) | 5 (55.6%) |
| 3. It was easy to access the programme | 0 | 1 (11.1%) | 0 | 1 (11.1%) | 7 (77.8%) |
| 4. I found the programme interesting | 0 | 1 (11.1%) | 2 (22.2%) | 1 (11.1%) | 5 (55.6%) |
| 5. I believe the programme will help me to live better on dialysis | 0 | 1 (11.1%) | 2 (22.2%) | 2 (22.2%) | 4 (44.4%) |
| 6. I enjoyed the programme | 0 | 1 (12.5%) | 2 (25%) | 2 (25%) | 3 (37.5%) |
| 7. I trusted the information in the materials | 1 (11.1%) | 0 | 0 | 2 (22.2%) | 6 (66.7%) |
| 8. I had no technical problems with the programme | 0 | 1 (11.1%) | 0 | 1 (11.1%) | 7 (77.8%) |
| 9. I enjoyed watching the films | 0 | 1 (12.5%) | 0 | 3 (37.5%) | 4 (50%) |
| 10. I could relate to the story films | 1 (11.1%) | 0 | 1 (11.1%) | 2 (22.2%) | 5 (55.6%) |
| 11. I understood how to do the activities | 1 (11.1%) | 0 | 0 | 2 (22.2%) | 6 (66.7%) |
| | Definitely not | Probably not | Unsure | Probably would | Definitely would |
| Would you use the materials and/or activities again in the future? | 0 | 0 | 1 (11.1%) | 3 (33.3%) | 5 (55.6%) |
| Would you recommend the programme to people just starting dialysis? | 0 | 0 | 0 | 2 (22.2%) | 7 (77.8%) |

Table 6. Post-programme responses about psychological support

| Question | I definitely missed being able to talk to a professional | Not sure, it might have been helpful to talk to a professional | Fine, I felt no need to talk to a professional |
|---|--|--|--|
| How do you feel about completing the programme without having a professional to talk to? | 0 | 3 (33.3%) | 6 (66.7%) |
| | Definitely not | Possibly | Definitely |
| Having completed this programme, how likely would you be to look for psychological support? | 2 (22.2%) | 4 (44.4%) | 3 (33.3%) |

Outcome measures

There was missing data for one participant in one scale (the KDQOLSF Sexual Function scale) at pre-intervention and follow-up, so the rate of missing data was 0.37% (1/273 [21 scales x 13 participants]) pre-intervention and 0.53% (1/189 [21 scales x 9 participants]) at follow-up. Out of 21 scales in total, 17 changed in a positive direction and two changes were significant: AAQ scores decreased, indicating improved psychological flexibility, and energy/fatigue increased, indicating more energy/less fatigue (Table 7).

Experiences of the programme

Table 8 shows all the responses to the post-intervention open-format questions except for one that was not about the programme. Simple inspection of responses about 'best things' showed participants found the programme content generally relatable and accessible. Suggested improvements included a special part for young adults, an interactive support group, better sound quality, and more case studies.

Table 7. Means (SDs) and tests of differences for baseline and follow-up measures among participants who completed follow-up (n=9)

| Scale | Baseline | Follow-up | Wilcoxon signed-rank test | |
|--|---------------|---------------|---------------------------|--------|
| | | | Z | p |
| <i>Process measures</i> | | | | |
| Psychological flexibility (AAQ) ^a | 25.00 (7.45) | 18.00 (4.36) | 2.38 | 0.02* |
| Acceptance of illness (AIS) | 21.67 (6.25) | 24.56 (6.98) | 1.13 | 0.26 |
| <i>Outcome measures</i> | | | | |
| <i>KDQOL-SF ESRD-targeted areas</i> | | | | |
| Symptoms | 68.98 (15.74) | 72.92 (18.01) | 0.211 | 0.83 |
| Effects of kidney disease | 42.01 (24.46) | 48.96 (21.31) | 1.404 | 0.16 |
| Burden of kidney disease | 29.17 (19.52) | 43.06 (19.87) | 1.706 | 0.09 |
| Work status | 22.22 (36.32) | 16.67 (35.36) | 1.000 | 0.32 |
| Cognitive function | 67.41 (15.07) | 57.78 (21.60) | 1.126 | 0.26 |
| Quality of social interaction | 67.41 (13.92) | 74.82 (15.56) | 1.256 | 0.21 |
| Sexual function | 37.50 (40.09) | 50.00 (40.09) | 0.948 | 0.34 |
| Sleep | 42.50 (27.10) | 53.70 (17.78) | 1.718 | 0.09 |
| Social support | 62.96 (28.60) | 72.22 (18.64) | 0.406 | 0.68 |
| Dialysis staff encouragement | 65.28 (31.73) | 73.61 (23.75) | 1.265 | 0.21 |
| Patient satisfaction with staff | 55.56 (32.28) | 61.11 (16.67) | 0.343 | 0.73 |
| <i>36-item health survey (SF-36) scores</i> | | | | |
| Physical functioning | 53.89 (20.73) | 53.75 (24.04) | 0.070 | 0.94 |
| Role-physical | 27.78 (42.29) | 27.78 (38.42) | 0.000 | 1.00 |
| Pain | 51.11 (22.03) | 60.00 (33.63) | 0.943 | 0.35 |
| General health | 38.33 (15.41) | 40.56 (17.93) | 0.426 | 0.67 |
| Emotional wellbeing | 57.33 (16.73) | 64.00 (10.95) | 0.985 | 0.33 |
| Role-emotional | 48.15 (44.44) | 62.96 (45.47) | 0.849 | 0.40 |
| Social functioning | 47.22 (19.54) | 52.78 (20.52) | 0.512 | 0.61 |
| Energy/fatigue | 23.33 (17.68) | 41.67 (17.32) | 2.677 | 0.01** |

Notes to Table 7:

SD=Standard Deviation; AAQ=Acceptance and Action Questionnaire; AIS=Acceptance of Illness Scale; KDQOL-SF=Kidney Disease Quality of Life-Short Form scales; ESRD=end stage renal disease; Alpha=Cronbach's Alpha.

a. Lower scores=greater flexibility. For all other measures, higher scores = greater acceptance of illness and higher quality of life.

* p<0.05; ** p<0.01;

Table 8. Responses to open-format questions in the post-intervention questionnaire

| |
|--|
| <p>What were the best things about the programme?</p> <ul style="list-style-type: none"> • ‘Different scenarios.’ • ‘The stories are very realistic and I could identify with some part of all of them.’ • ‘The size of each video was perfect, not too long as to get bored but long enough to get the message across. Having experienced everything that was covered I could identify with everyone’s story. Any new or old to dialysis would benefit from the program.’ • ‘Each person had issues that I related to. It was nice to see how they coped with them.’ • ‘Makes you take stock and realise you’re not on your own with the feelings.’ • ‘That even though the four people featured in the videos were different to me (i.e. age, gender, life experiences etc) I shared their experiences and issues around haemodialysis and this helped me engage with the videos.’ • ‘Easy to listen to.’ • ‘Simple to follow characters I had empathy with.’ |
| <p>How could the programme be improved?</p> <ul style="list-style-type: none"> • ‘A special part of the programme designated for young adults.’ • ‘Regular updates?’ • ‘As a follow up to the program patients would need details of resources available to them. From my experience within the [place name] area those resources are sadly lacking.’ • ‘Could possibly make an interactive support group of people using the program.’ • ‘More case studies.’ • ‘As the programme was so good it's hard for me to think of any improvements. The only small thing I could think of was that the sound quality on some of the videos could be improved.’ • ‘Couldn't be improved.’ • ‘Perhaps more characters with different problems.’ |
| <p>Anything else you would like to add about the programme or how it affected you</p> <ul style="list-style-type: none"> • ‘I have been through some of these ideas, such as mindfulness and breathing, which really helps.’ • ‘I found it very interesting, I have felt the same as all the people in the videos, especially resentment.’ • ‘The program reinforced what I have been through and still going through. Also made me aware that I'm not on my own with the feelings I have towards dialysis.’ • ‘I’m going to look into ways of using my time on dialysis as useful time instead of being annoyed and bored. Going to work on being frustrated that my illness prevents me from working or travelling.’ • ‘I wish it had been available at an earlier stage.’ • ‘I found it very comforting that all the issues I was experiencing with haemodialysis were very normal and were being experienced by other people. It helped me to feel less lonely. Thank you.’ • ‘Interesting to discover other dialysis patients felt like me.’ • ‘I found it interesting.’ |

Of 13 participants invited, five were interviewed, one was not interviewed because of illness, one could not commit to a date because of clinic appointments, and six did not respond to invitations or could not arrange convenient dates. Analysis of interview transcripts identified four themes: 1) *content*, including coverage of issues, personal stories, exercises and suggested missing content; 2) *format*, including video and cartoons, text, length of material and programme, personal contact with professionals, ways of watching, and time spent on programme; 3) *personal benefits*; and 4) *applications*. These themes were consistent with responses to the post-intervention open-format questions, suggesting that participants who were interviewed were broadly representative (Full interview data is available from <https://www.isrctn.com/ISRCTN10070371>).

Discussing *content*, participants described how they identified with the issues addressed, and how the personal stories made the issues more accessible and authentic:

“... it was very good because it was very simple [...] the way it was presented, it would have answered a lot of the questions that I had and the way that I felt right at the very beginning.” (Elizabeth, lines 54-56)

“I thought they were interesting, and it’s good having different people from different walks of life doing it, again so everyone could identify with them, so that was good.” (John, lines 99-100)

One issue not addressed by the programme that participants felt could be included (while recognising this would not be suitable for people before starting dialysis) was fear of dying while on dialysis.

Discussing *format*, participants described how video made the material accessible and cartoons gave a light, informal feel:

“... the videos are quite accessible, and I thought it was a good way of doing it ...” (John, line 37)

“... because it's animation, it wasn't done jokingly, but it had a bit of, you know, a lightness of touch to it. So it wasn't sort of, you know, depressive or anything, you know. So, I think the animation was a good choice definitely.” (Carol, lines 45-47)

“... it comes over as very personal, but not directly, you weren't staring at somebody's face, and the cartoon-type-based video is, often it kept it informal, but the fact that you've got these real-life stories [...] I think that format, it's perfect.” (Peter, lines 102-104, 124)

Participants described how the programme had a good video-text balance, was about the right length, that they spent 25 to 45 minutes per week on the programme, and that it did not matter that there was no personal contact with a health professional. Two participants described *personal benefits* they experienced, one by helping with management of eating to reduce body-mass index for kidney transplant, the other to accept the change from home peritoneal dialysis to in-centre haemodialysis. Participants all felt the most useful *application* was for people beginning dialysis and that the programme should be available in dialysis units and the community, including for people to view in groups, but

also suggested other versions could be developed for pre-dialysis, pre-transplant and peritoneal dialysis.

Discussion

The programme recruited 13 participants; 65% of those eligible who expressed interest. Of the 13 recruited, 11 (85%) stayed for at least half the programme and nine (69%) for the whole programme and all study measures. Weekly engagement was 85% for weeks 1 and 2 and 77% for weeks 3 and 4. Use of activities was 94.4%. All four story films and nine of 12 explainer films received positive evaluations from at least 75% of participants. Eight of 11 statements about the programme were positively endorsed by at least 75% of participants, and 8/9 participants (88.9%) found the programme easy to use, understood how it worked, found it easy to access, trusted the information, had no technical difficulties and understood the activities. All participants would recommend the programme to people starting dialysis. Based on the very low level of missing data, the outcome measures were feasible and acceptable, and the direction of change was positive for 17/21 scales, with significant improvements in psychological flexibility and energy/fatigue.

The study therefore achieved targets for number recruited (13 – target 10), retention for half the programme (85% - target 80%), weekly engagement (85% and 77% - target 75%) and proportion of missing data in outcome measures (0.37% and 0.53% - target below 10%). The results approached but did not achieve targets for recruitment rate (65% - target 75%) and retention for the whole programme (69% - target 80%). The explainer films that did not achieve 75% positive evaluations (*identifying values*, *flexible perspective-taking*, and *mindful breathing*) nevertheless achieved 63.6%, 63.6% and 70% positive evaluations respectively, and the statements that did not achieve 75% agreement (finding the programme interesting, believing it would help to live better on dialysis, and enjoying the programme) nevertheless achieved 66.7%, 66.7% and 62.5% agreement, respectively.

People who had to wait to begin the programme were less likely to engage and health or treatment complications were the main known reasons for non-participation and drop-out, so recruitment and engagement could probably be improved by face-to-face contact (Hoefnagels et al., 2020) and by enabling participants to begin the programme when ready and take breaks if necessary. A strength of online programmes is enabling participants to access them flexibly and haemodialysis populations often have significant constraints on their availability. In the present version, flexibility was restricted slightly by the fact participants were emailed individually with links to each week's materials, so future, scaled-up versions could enable even more flexible access and use.

Qualitative feedback showed that participants found the programme relatable and accessible, with multiple examples of ways participants benefitted personally. Suggested improvements included a special part for young adults, interactive elements, and more case studies. The interviews emphasised the value of using personal stories and cartoons to present serious issues in a light way, consistent with previous evidence about how stories, cartoons and fictional figures encourage metaphor use in ACT interventions (Gaudio & Busch, 2013; Gillanders & Gillanders, 2014; Vilardaga et al., 2020). Interviewees suggested the programme would be most useful when beginning dialysis but that other versions could

be produced for pre-dialysis, pre-transplant and peritoneal dialysis, and that the programme should be available in dialysis units and the community.

Online resources are needed to supplement the psychological support available in dialysis units, many of which presently have fewer psychosocial support staff than recommended (Seekles et al., 2019). The results illustrate the value of tailoring ACT-based interventions for specific user groups and involving patients in programme development (Elander et al., 2021). Versions tailored for people receiving peritoneal dialysis, preparing to begin dialysis, preparing for kidney transplantation, and young people preparing to transition to adult care could all be developed.

Study limitations included: participants had not all recently begun dialysis so the sample was not the exact target group; there was no control group; the follow-up period was relatively short; participants were rewarded for completing the trial; and the results were likely affected by 'survivor bias', as most of the data was from participants who completed the study. Also, only two participants were from minority ethnic backgrounds whereas kidney disease is more prevalent and with poorer outcomes among visible minorities (Mathur et al., 2019). Two of the stories in the programme portrayed members of minority ethnic groups (Jayden and Naadiya) but a proactive strategy to recruit minority participants will be needed in future, probably by recruiting in-person at dialysis centres and setting targets for sample composition.

Notwithstanding those limitations and the fact that some of the targets were not achieved, the results suggest online, video-based ACT interventions are feasible and acceptable for people receiving kidney haemodialysis, and the results provide pilot data for a larger trial.

Authors' contributions

All the authors contributed to the conception and design of the study. EC oversaw the design and development of the programme. CS and MA delivered the programme and collected the data. JE and MA conducted the interviews. JE led the data analysis and wrote the manuscript. All the authors contributed to the interpretation of findings, review and editing of the manuscript, and all the authors approved the final manuscript for submission.

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Conflicts of interest declaration

The authors all have no conflicts of interest to declare.

Note

1. Seven activities were used by all nine participants (7 x 9); four activities were used by eight participants (4 x 8); one activity was used by seven participants (1 x 7). Therefore $(7 \times 9) + (4 \times 8) + (1 \times 7) = 63 + 32 + 7 = 102 / 108$ [12 activities x 9 participants] = 94.4%.

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