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RESEARCH **Open Access**

An embedded qualitative study of the experiences of people with dementia, their caregivers and volunteer older adults who participated in the CREST resilience-building psychosocial intervention

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Abstract

Background A novel *C*omplex *RE*silience-building psycho*S*ocial interven*T*ion (CREST) targeted at people with dementia, their informal carers, general practitioners and the wider community with the aim of increasing resilience and strengthening the personal attributes or external assets of people with dementia living at home, in the community, was developed. It included three components: cognitive stimulation therapy (CST), physical exercise and dementia education. A non-randomised feasibility study was conducted of the CREST intervention, the aim of which was to inform the design of a future randomised controlled trial. This article presents the findings from the qualitative component of the CREST intervention feasibility study, describing the experience of the people with dementia and their caregivers who participated and the volunteer older adults who supported the intervention.

Methods A descriptive qualitative research approach using semi-structured interviews was undertaken. Key stakeholders (people with dementia ($n=9$), their caregivers ($n=9$) and the volunteer older adults from the physical exercise component ($n=9$)) were interviewed about the intervention and the perceived impact of their participation.

Results The social aspect of the CREST intervention proved to be important for all three groups. Attendance remained high throughout the intervention. The people with dementia spoke positively about their participation in the CST and exercise components of the CREST intervention. The caregivers liked receiving coping strategies focused on how to communicate better with the person they cared for and how to better manage their own self-care and they liked the group element of the programme. The volunteer older adults supported the people with dementia in taking part in the exercise component, motivating them to do the exercises and helping with social interaction within the group. The volunteers gained exposure to the illness and as a result understood more about dementia and felt better equipped to communicate and deal with people with dementia.

Conclusion Participation in the CREST intervention produced a positive impact on all three groups. The social element of the intervention was noted by everybody and was regarded as being beneficial. Qualitative insights

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emphasised the value of embedding qualitative research within feasibility studies to inform future intervention design. Further research should focus on conducting a full-scale randomised controlled trial to evaluate CREST's effectiveness and explore its application to individuals with more advanced dementia.

Trial registration ISRCTN25294519.

Keywords Dementia, CREST intervention, Cognitive stimulation therapy, Physical Exercise, People with dementia, Caregivers, Volunteer older adults

Background

It is estimated that globally the number of people with dementia will increase from 57.4 million cases in 2019 to 152.8 million cases in 2050 [1]. In Ireland, it is expected that the overall number of people with dementia will more than double from an estimated 55,000 in 2018 to 141,200 in 2050 [2].

Living with dementia can present significant challenges for the person with dementia and their informal caregivers, and much focus has been placed on strategies to improve their daily experience and enhance their ability to face such challenges [3, 4]. In particular, resilience-building interventions strengthen internal and external assets to allow a person to adapt to challenges or stress and remain psychologically, socially, and physically healthy [5, 6]. Within the context of dementia, such assets may include relationships with family or friends, connections within their community, (re)gaining personal control, and maintaining a fit and healthy lifestyle [7–10]. Thus, optimal strategies to build resilience in people with dementia are those which operate at the personal and interpersonal level [9, 11–13].

'Multicomponent' psychosocial interventions, which target psychological and physical assets, have demonstrated particular benefits for people with dementia [14]. Cognitive Stimulation Therapy (CST) delivers a range of themed activities in a group context and can enhance cognitive functioning, social interactions, and quality-of-life in people with mild to moderate dementia [15–17]. Similarly, physical exercise can improve physical function, mobility and cognition in people with mild dementia or cognitive impairment [14, 18, 19], and exercising in a group context provides additional benefits such as interaction and social connectedness [14, 20, 21]. Research suggests that volunteer supported group exercise programmes can be successful in engaging people with cognitive decline and dementia and can have an important role in building relationships between the volunteers and the participants with dementia [22]. In addition, volunteers can improve their knowledge and attitudes towards dementia through training for and delivery of activity-based interventions [23]. Externally, public dementia education can improve the daily experience of people with dementia, by strengthening the knowledge and communication skills of their key supporters, including caregivers, general practitioners (GPs) and the community [24–26].

These three aforementioned components (CST, physical exercise, and dementia education) were incorporated into a novel *C*omplex *RE*silience-building psycho*S*ocial interven*T*ion (CREST) targeted at people with dementia who were living at home, their informal carers, GPs and the wider community with the aim of increasing resilience and strengthening the personal attributes or external assets of people with dementia [27]. A non-randomised feasibility study was conducted of the CREST intervention, the aim of which was to inform the design of a future randomised controlled trial (RCT) [27]. This article presents the findings from the qualitative component of the CREST intervention feasibility study. We aim to describe the experience of the people with dementia and their caregivers who took part in CREST and the volunteer older adults who supported the people with dementia in the physical exercise component and the perceived impact of their participation.

Methods

Study design

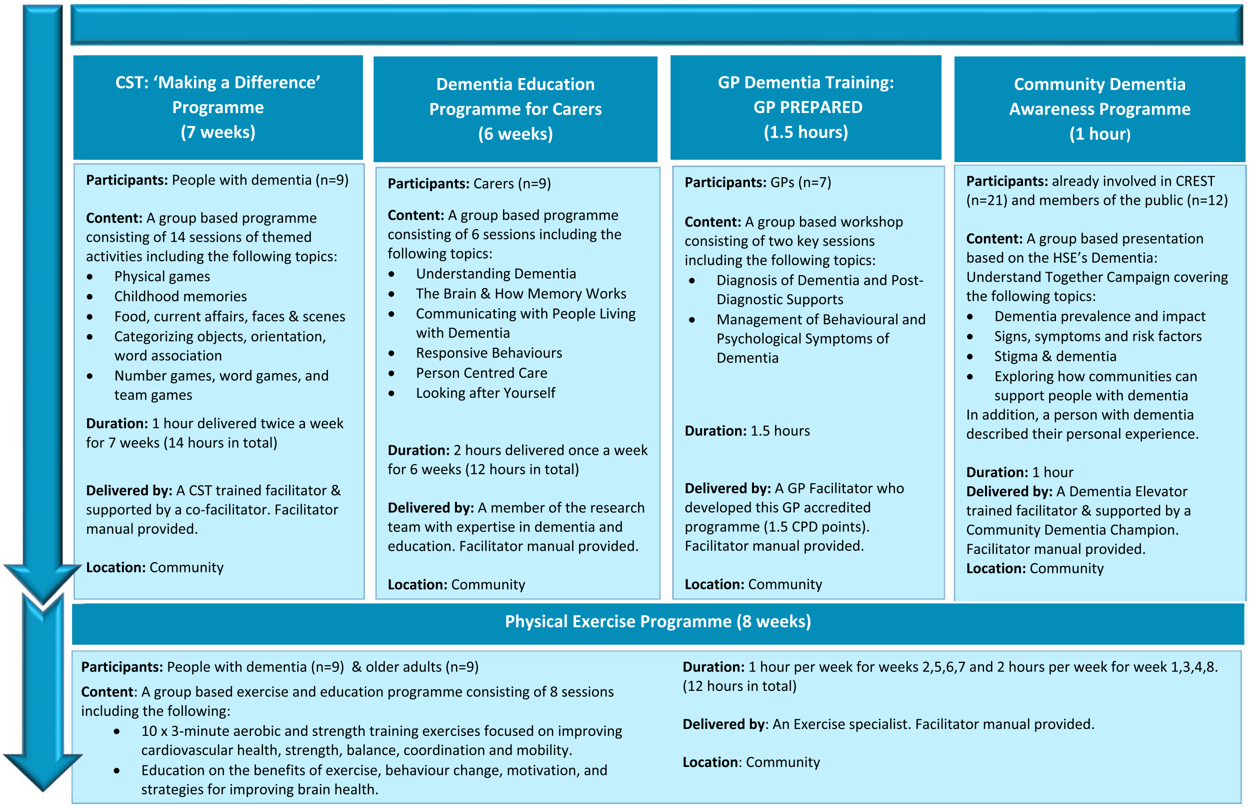
A descriptive qualitative research approach [28] using semi-structured interviews was undertaken. This approach was chosen to empower participants by allowing them to express their views and experiences in their own words and to enable the gathering of straightforward accounts, capturing a descriptive narrative of findings in everyday language.

The CREST intervention

The three core components of the CREST intervention were delivered over a 15-week period to the people with dementia (CST, physical exercise) and the caregivers (dementia education) (Fig. 1). The volunteer older adults supported the people with dementia during the physical exercise component of the intervention.

Cognitive stimulation therapy

The CST component for people with dementia consisted of 14 CST sessions across seven weeks (two 1-hour sessions per week) (Fig. 1). The sessions were delivered in a



CST: 'Making a Difference' Programme (7 weeks)

Participants: People with dementia (n=9)

Content: A group based programme consisting of 14 sessions of themed activities including the following topics:

- Physical games
- Childhood memories
- Food, current affairs, faces & scenes
- Categorizing objects, orientation, word association
- Number games, word games, and team games

Duration: 1 hour delivered twice a week for 7 weeks (14 hours in total)

Delivered by: A CST trained facilitator & supported by a co-facilitator. Facilitator manual provided.

Location: Community

Dementia Education Programme for Carers (6 weeks)

Participants: Carers (n=9)

Content: A group based programme consisting of 6 sessions including the following topics:

- Understanding Dementia
- The Brain & How Memory Works
- Communicating with People Living with Dementia
- Responsive Behaviours
- Person Centred Care
- Looking after Yourself

Duration: 2 hours delivered once a week for 6 weeks (12 hours in total)

Delivered by: A member of the research team with expertise in dementia and education. Facilitator manual provided.

Location: Community

GP Dementia Training: GP PREPARED (1.5 hours)

Participants: GPs (n=7)

Content: A group based workshop consisting of two key sessions including the following topics:

- Diagnosis of Dementia and Post-Diagnostic Supports
- Management of Behavioural and Psychological Symptoms of Dementia

Duration: 1.5 hours

Delivered by: A GP Facilitator who developed this GP accredited programme (1.5 CPD points). Facilitator manual provided.

Location: Community

Community Dementia Awareness Programme (1 hour)

Participants: already involved in CREST (n=21) and members of the public (n=12)

Content: A group based presentation based on the HSE's Dementia: Understand Together Campaign covering the following topics:

- Dementia prevalence and impact
- Signs, symptoms and risk factors
- Stigma & dementia
- Exploring how communities can support people with dementia

In addition, a person with dementia described their personal experience.

Duration: 1 hour

Delivered by: A Dementia Elevator trained facilitator & supported by a Community Dementia Champion. Facilitator manual provided.

Location: Community

Physical Exercise Programme (8 weeks)

Participants: People with dementia (n=9) & older adults (n=9)

Content: A group based exercise and education programme consisting of 8 sessions including the following:

- 10 x 3-minute aerobic and strength training exercises focused on improving cardiovascular health, strength, balance, coordination and mobility.
- Education on the benefits of exercise, behaviour change, motivation, and strategies for improving brain health.

Duration: 1 hour per week for weeks 2,5,6,7 and 2 hours per week for week 1,3,4,8. (12 hours in total)

Delivered by: An Exercise specialist. Facilitator manual provided.

Location: Community

Fig. 1 Overview of the CREST Intervention

group format by two facilitators and two co-facilitators, and centred on themed activities such as childhood memories, current affairs, and number games [29].

Physical exercise

The exercise component for the people with dementia consisted of physical exercise (8 sessions, one hour per week) and exercise education (4 sessions, one hour each in weeks 1, 3, 4, 8) (Fig. 1). This was derived from the PRINCE exercise programme [30] and modified to the needs of people with dementia. Both elements were delivered in a group format by an exercise facilitator and co-facilitator. The education sessions explored the benefits of exercise and strategies to maintain brain health. The exercise sessions included a circuit of ten 3-minute exercise stations which could be adjusted to individual needs (e.g., bicep curls using lighter weights), plus a warm-up and cool-down. For additional social engagement, each person with dementia was paired with a volunteer older adult from the community (an exercise partner), whose role was primarily to support and encourage the person with dementia to complete the exercises, to help them record their performance, to help with social interaction and engagement and to have fun.

Dementia education for caregivers

The education component for caregivers consisted of six sessions (two hours, once per week), delivered in a university campus classroom by two members of the research team with expertise in dementia, nursing, and education. Materials were drawn from the *DARES* programme [31] and *The Alzheimer Society of Ireland*'s 'Family Carer Training' programme [32]. Sessions focused on increasing the caregivers' knowledge of dementia and developing skills to manage dementia, e.g., types of dementia, communication strategies for engaging with people with dementia, and managing their own health needs (e.g., self-care and the impact of caregiving). The sessions were delivered in a group format to allow the caregivers to meet and share their experiences.

There were two more components to CREST: a community dementia awareness programme, which was a one-off event to inform the public about dementia and a GP educational workshop. The findings of these two components will be reported elsewhere.

Recruitment

People with dementia and their caregivers

People with mild to moderate dementia ($n = 10$) and their caregiver ($n = 10$) were recruited to the CREST intervention through GP practices and local dementia support and advocacy groups and networks (e.g., The Alzheimer's Society of Ireland, Western Alzheimer's). The recruitment process has been described in detail in the study protocol [27]. Inclusion criteria included community dwelling adults aged ≥ 60 years, who had the capacity to provide informed consent independently and with either (1) A formal diagnosis of mild to moderate dementia; or (2) Prescribed dementia medications; or (3) Their GP believed the person has memory problems and the person has a provisional diagnosis of dementia based on the DSM-IV criteria. All participants met inclusion criteria 1 and 2. They were also required to have their primary caregiver agree to participate in aspects of the CREST intervention.

Volunteer older adults

A wide range of local community organisations and groups focusing on older adults, dementia, advocacy, volunteering, and health were approached, for example Age Friendly Ireland, active retirement groups, Age Action, COPE and Western Alzheimer's. Methods employed included leaflets, posters and community recruitment information talks. Inclusion criteria included older adults who (1) Were over 60 years of age; (2) Did not have a diagnosis of dementia; (3) Did not have any medical condition that could prevent them from undertaking the exercise programme and (4) Were able to speak and read English and give informed consent. Older Adults, that expressed an interest in taking part, were contacted by the research team and their eligibility was confirmed. They were then given a brief overview of the study and provided with an information pack.

Participants – people with dementia and their caregivers

Ten people with dementia and their caregivers were successfully recruited to the study, however, one pair withdrew after the first week due to illness, so nine people with dementia and their caregiver received the CREST intervention. There were five male and four female participants in the people with dementia group with a mean age of 76 years. Baseline Mini-Mental State Exam (MMSE) scores [33] indicated mild to moderate-stage dementia ($M = 20.40$, $SD = 4.90$), and the majority ($n = 7$) reported having memory problems for fewer than four years. The majority of carers were female with a mean age of 57.9 years. Most carers ($n = 5$) were the spouse of the person with dementia and lived with the person they cared for. Further demographic details are presented in Table 1.

Volunteer older adults

A total of nine volunteer older adults joined the CREST exercise programme, to provide support and encouragement to the people with dementia. There were almost an even numbers of male ($n = 5$) and female ($n = 4$) participants aged 60–69 years ($n = 4$), 70–79 years ($n = 4$) and > 80 years ($n = 1$). Further demographic details are presented in Table 2.

Data collection

Interview procedure

Semi-structured interviews were conducted with all participants. They were informed about the interviews at the same time they were informed about the trial and they understood that they were part of a feasibility study, which included providing feedback on various aspects of the trial. The researchers' motivations for conducting the study were shared, emphasising the goal of improving dementia care interventions and understanding participants' experiences to inform future research. Participation in the interviews was not mandatory, and participants were assured they could opt out of the interviews at any point if they so wished without any repercussions. Informed explicit consent was obtained from all participants at the start of the trial, covering all data collection including interviews, recordings, and the publication of quotes. Participants were assured that their data would be pseudo-anonymised and that all information would be kept private and confidential. The interview guides for the people with dementia and their caregivers were developed with the CORTE framework [34] and reviewed by a person with dementia and caregiver from the study advisory group to ensure they met the needs of the group. Examples of the questions asked have been included as supplementary material. Interviews were conducted by trained qualitative female researchers (DC, PD, SS, NG) who were part of the research team, two of whom held PhDs and two with Master's degrees and who had gotten to know the participants through the intervention. Field notes were made after the interviews and focus groups. All interviewees were given the opportunity to ask questions prior to starting the interview. All interviews were audio-recorded with the permission of the participant(s), to facilitate accurate transcription and analysis. Individual and group interviews were conducted at multiple stages of the study. Mid-intervention interviews were conducted approximately halfway through each intervention component to gather insights on participants' experiences and emerging themes. Follow-up

Table 1 Characteristics of the people with dementia and their caregivers

		People with dementia ($n = 9$)	**Caregivers ($n = 9$)**
Sex	Female	4	8
	Male	5	1
Age	30–39	-	1
	40–49	-	2
	50–59	-	3
	60–69	3	2
	70–79	4	1
	80–89	2	0
	Mean age	76 years (SD = 7.81)	57.9 years (SD = 12.89)
Mini-Mental State Exam (MMSE) score	Mean score	20.40 (SD = 4.90)	N/A
Relationship to person with dementia	Child	4	
	Spouse	5	
Time giving/ receiving care	0–4 years	7	
	5–9 years	1	
	(Missing)	1	
Living arrangement	Own home	1	-
	Living with carer	8	-
Education attained	Primary level	1	1
	Secondary level	4	1
	Third level	3	5
	Other (e.g., professional)	1	2
Employment status	Employed	0	3
	Homemaker	1	1
	Unemployed	0	1
	Retired	8	4

interviews took place 1–2 weeks after the completion of the intervention to explore participants' reflections and overall perceptions. Information about the interviews is given in Table 3.

Interview setting

The focus groups and individual interviews were conducted either at the venue where the intervention was being run or in participants' homes, with only the participants and researchers present.

Data analysis

NVivo 12.0 (QSR International, Melbourne, Australia) was used to organise and retrieve the qualitative data. Each respective data set was analysed and coded using directed qualitative content analysis, focusing on the relevance of the data to the research aims and grouping them into themes [35]. Data analysis was conducted in an iterative process as the feasibility study was ongoing, which allowed us to identify and explore emerging themes in subsequent interviews. Each individual data set was initially coded independently (DC, SS, PD, GOS) and the codes were then checked by a second member of the qualitative team (DC, SS, PD, GOS). Peer debriefing throughout the analysis process with the research team helped to clarify and resolve any coding issues. Any discrepancies were discussed and resolved. The criteria outlined by Lincoln & Guba [36] were used to ensure rigour.

Ethics

Ethical approval for the study was granted by the University of Galway Research Ethics Committee (Ref: 16-Feb-03). Consent to participate was obtained from all participants, each of whom had the capacity to provide informed consent independently.

Results

The data are presented under three main themes: (1) Motivation to participate in CREST, (2) Experience of the different components of the CREST intervention, and (3) Perceived impact of the intervention on their lives. These themes encompass the experiences of people with

Table 2 Characteristics of the volunteer older adults

	Volunteer older adults (*n*=9)
Sex	
Male	5
Female	4
Age (years)	
60-69	4
70-79	4
80+	1
Highest level of education attained	
Secondary education	5
Technical/vocational qualification	1
Third level degree or above	1
Professional qualification	2
Completed dementia education	
Yes	1
No	8
Training type	
Face-to-face	1
Experience of interacting with people with dementia	
Yes	7
No	2
Who was the person you were interacting with	
Relative	4
Member of the general public	3

dementia, their caregivers, and the volunteer older adults. Because the caregivers also discussed their perception of the people with dementia's experience of CREST, some of their feedback is included under the findings from the people with dementia.

Theme 1. Motivation to participate in CREST

People with dementia

Participants with dementia were motivated to join CREST for various reasons, including personal benefit, and encouragement from caregivers.

> *'I can't remember that far back now. But my gut feeling is that the program was being supervised so therefore I felt I should participate … that it would benefit me … Which I feel it did.' (Person with dementia P4, follow-up interview).*
> *'Well, [caregiver name], my wife is the instigator of that. She thought I was just losing a little bit of my memory at times … I'm fine, I think … So that was why I got involved.' (Person with dementia P8, follow-up interview).*

One participant described how their caregiver suggested they take part because it was a way of *'giving something back'* (Person with dementia P6) to their community by participating in the research.

Some saw it as an educational opportunity, while others participated because of a family tradition of community involvement.

> *'And it was education as well. You know what I mean. And you're always learning all your life so you are.' (Person with dementia P3, follow-up interview).*
> *'I'm a great believer in getting involved with you know kind of because that was something that I grew up like. My mother was a great woman for getting involved with everything.' (Person with dementia P1, follow-up interview).*

Caregivers

Caregivers were primarily motivated to gain a better understanding of dementia to support their loved ones.

Table 3 Information about the interviews conducted with each group

Intervention component	**Individual/group interview**	**People with dementia (*n*) (duration)**	**Caregivers (*n*) (duration)**	**Volunteer older adults (*n*) (duration)**
CST	Group interview (week 4 – mid intervention - of CST component)	✓ (9) (30 min)		
Exercise	Group interview (week 5 - mid intervention - of exercise component) Group interview (end of exercise component)	✓ (9) (45 min)		✓ (9) (74 min)
Caregiver Education	Group (week 4 - mid intervention - of the education component)		✓ (5) (30 min)	
Post intervention	Individual follow-up interviews	✓ (9) (20–40 min)	✓ (9) (40–60 min)	

> *'It was to try and get an understanding of Alzheimer's and dementia as a whole ... So [joining CREST] was to try and kind of get an understanding of it ... So, when you were saying that there was an educational part of this for the carers I was like "yeah, I definitely want to do that"' (Caregiver C1, follow-up interview).*
> *'I just thought it would be a really good opportunity to go and learn more about how to deal with things ...' (Caregiver C5, follow-up interview).*

Two participants found that the intervention came at an ideal time, as their loved one had just been diagnosed with dementia and they did not know how to proceed. Taking part in the research provided an opportunity for both of them to benefit.

> *'Because my husband I noticed was losing his memory, and I didn't know much about it whether you call it dementia or whether you call it loss of memory or which way to go' (Caregiver C8, follow-up interview).*

Many caregivers also indicated a secondary desire to participate in the CREST intervention, which was to meet other caregivers who would understand their experiences. One caregiver explained this succinctly:

> *'I guess I wanted answers...From my perspective being the carer... And maybe a bit of, you know, just to meet other carers whose loved ones have dementia and whatever...Like, just an outlet for me...I wanted to meet the others and get their similar situations and "How do you...?", "What do you do if - just say - whoever had a bad morning, you know?' (Caregiver C4, follow-up interview).*

Volunteer older adults

The volunteer older adults were not explicitly asked why they decided to volunteer for the exercise programme, however, they demonstrated high levels of motivation to participate in turning up weekly for the classes and engaging in the activities with enthusiasm. The volunteers were asked to provide support and encouragement to the person with dementia to undertake the exercises and if necessary, to prompt the person to complete the exercises. Prior to the exercise programme they took part in a one-off dementia training and community dementia awareness evening whereby they could learn about how best to communicate with a person with dementia, about their role in the exercise programme and information generally about dementia. They also took part in a 'meet and greet' event whereby they met the people with dementia. All of the volunteer older adults committed their time to these events in addition to the weekly exercise programme. One of the volunteer older adults explained that their motivation for participating in the exercise programme was to increase their knowledge and understanding of dementia.

> *'So I was in it for myself as well you know and seeing if it could make me understand a little better. And that's really my... I don't mind participating in it but I want to be better when I leave it you know so that I can meet any situation that comes' [Older adult OA8].*

Theme 2. Experience of the different components of the CREST intervention

People with dementia

The people with dementia took part in the CST and exercise components of the intervention. The predominant theme that emerged from both programmes was the high level of enjoyment the people with dementia gained from the social aspects of the sessions. They enjoyed meeting new people and some commented on how much they looked forward to the sessions. One participant described the exercise programme as *"a bit like a social club"* (Person with dementia P4, mid-intervention interview) and another the CST programme as "a bit of craic" (an Irish colloquial term for having fun/enjoyment) (Person with dementia P2, mid-intervention interview).

> *'I looked forward to meeting them every day it was on ... You'd be chatting to them and saying, "How did the week go?" and you know they were in the same situation as I was' (Person with dementia P8, mid-intervention interview for exercise programme).*
> *'Well [I liked] the meeting of other people, really and truly. I did and they're all so positive. And they're all like ourselves' (Person with dementia P3, follow-up interview).*

Pairing the people with dementia with volunteer older adults in the exercise programme enhanced participants' enjoyment. The volunteers provided motivation and improved social interaction and because the same pairs remained together throughout the programme it helped to build a relationship between them.

> *'Well [my exercise partner] was very good ... done a very good job. It was the same person you were dealing with each week, which was great. You got more out of it. And you could have a chat and things like that.' (Person with dementia P2, follow-up interview).*

The caregivers echoed the people with dementia in describing their enjoyment of both the CST and exercise programmes. They remarked that the people they cared for were enthusiastic about attending the sessions; they attributed the new-found enthusiasm to the group members being friendly.

> *'Oh definitely. [The person I care for] would be excited about going to the class every week. He made new friends. And he'd be like coming home saying "Oh I met lovely people" … He really enjoyed it every day that he went' (Caregiver 2, mid-intervention interview).*

Overall, the sense of camaraderie and the opportunity to connect with peers and volunteers enhanced participants' overall satisfaction and engagement with CREST.

Caregivers

The caregivers took part in the caregiver education component of the CREST intervention. The group-based nature of the education sessions was crucial to their enjoyment of the component: they appreciated meeting others who could understand their situation and found benefit in sharing their experiences and advice with each other.

> *'…there's a group of us who are in the same situation. It was nice to have that inclusiveness to kind of go with and say "Look, we're all here for a common goal" … It was we're all here to learn, to understand. It was nice to feel that… it was a nice group to have because you weren't sitting there going, "Here we go, another story for 20 minutes". It was a matter of actually, what they're saying, I can relate to, or what they're saying they can relate to' (Caregiver C1, follow-up interview).*

The caregivers found the content of the education sessions easy to understand and helpful to their situations. Specifically, they highlighted the usefulness of learning about different types of dementia and the importance of being tolerant and patient while interacting with the person they care for.

> *'Yeah, it has helped me a lot… it's helped me to see things how they are and I have to try and accept like you know the way [the person I care for] is …But the classes did [help]. It told you the different types of dementia and the different stages and what to expect … I learned at the course to be more understanding. And I try. (Caregiver C2, follow-up interview)*
> *'I feel I'm more tolerant. I'm not as impatient with or as frustrated….' (Caregiver C1, follow-up interview).*

Caregivers found the session focusing on effective communication with a person with dementia particularly useful.

> *'[Now] I find that if I have a smiley face and a softer voice, it defuses the situation much better … I hadn't thought about that kind of communication' (Caregiver C7, follow-up interview).*

Finally, the participants cherished the camaraderie in the caregiver group to the extent that they planned to continue meeting by themselves after the intervention had finished. They created a social messaging group in order to arrange regular meetups. For some participants, such meetups would offer an informal support network to 'compare notes', when they had questions or needed help from the group.

> *'…It's important now, I think, for us to continue meeting the ones that we have already met… As carers and we can compare notes and things like that' (Caregiver C8, follow-up interview).*

Volunteer older adults

Overall, the volunteer older adults enjoyed supporting the people with dementia in the exercise programme. They all agreed that the social interaction was important and they took pleasure in seeing the improvement among the people with dementia with each week of the programme.

> *'You could see the improvement in people with the different activities… From a physical point of view and also from a social point of view. The social interaction was getting better all the time' (Older adult OA1).*

In addition, many could see improvements in the fitness level of the people with dementia.

'They were coming on and getting fitter because they were here' (Older adult OA6).

Finally, the group expressed disappointment that the exercise programme had ended.

> *'It's a pity really that it came to an end after eight weeks, mainly for those people because they were improving all the time. They were getting fitter. They were getting used to the people.' (Older adult OA3).*

The positive effects on both the volunteers and participants indicate mutual benefits, as the volunteers gained valuable experience and a sense of fulfilment while helping ensure the success of the exercise programme.

Theme 3. Perceived impact of the intervention on their lives

People with dementia

Cognitive changes in people with memory problems after taking part in the CST component was not assessed; however, the data revealed that some participants perceived personal improvements, which they attributed to attending the CST sessions. These improvements included better concentration, more motivation to take up new hobbies, and more confidence.

> *'It helped [my concentration] because I was very bad at the beginning but by the end … I felt I got something out of it' (Person with dementia P5, follow-up interview).*

Some of the caregivers also noted changes in how the person that they cared for engaged and changes in their concentration.

> *'Once she got the diagnosis, she started finding it hard to find the words and just kind of gave up on reading. Like newspapers, she'd flick through them and wouldn't actually pay attention to them. Whereas once she started doing the CST … she'd always be reading a newspaper or a magazine or something. So, it really has boosted her confidence. It's a huge difference' (Caregiver 1, mid-intervention interview).*

Though the CREST intervention was not assessing changes or improvements in physical health during the exercise programme, some people with dementia remarked that they felt their health had improved, with some noting improved fitness or flexibility, reduced breathlessness, and better-quality sleep:

> *'I'm sleeping better because I'm moving more, I'm more tired' (Person with dementia P1, follow-up interview).*
> *'I still do the exercises that I picked up there, all the stretches when I get up in the morning, before I get out of the bed. I'm doing my different movements and everything. Trying to keep the muscles supple and workable' (Person with dementia P8, follow-up interview).*

A couple of the caregivers remarked that the person they cared for was steadily taking on more exercise while enrolled in the CREST intervention, and some planned to encourage them to continue doing exercises at home.

> *'We try and do a little bit every day. Now he is walking more up and down. When the weather was bad, he'd walk around down to the driveway or down the garden and around so he'd get a bit of walking. But what I want him to do now is to do those exercises because they are different to walking. You get different benefits …' (Caregiver 7, follow-up interview).*

Some of the people with dementia expressed their disappointment that the CREST intervention had ended and some expressed a wish that it would be available again in the future.

> *'I mean I was devastated when I was told it was going to be gone kind of thing you know' (Person with dementia P2, follow-up interview).*

The perceived cognitive and physical improvements reports by participants with dementia suggest that the CREST intervention may have contributed to enhancing their quality of life.

Caregivers

All of the caregivers felt they had more knowledge and a better understanding of dementia following the educational component and this helped them understand how to better deal with situations.

> *'I literally had no idea. I just assumed dementia was dementia and that was it. There was no other types to it… It was brilliant because it was when you know the type you're dealing with you can alter how you deal with it… And you can understand [the person I care for] from that… I'd say it made it easier' (Caregiver C1, follow-up interview).*

One caregiver mentioned that the CREST intervention would have been particularly helpful when she first became a caregiver, and felt it would benefit people in a similar position:

> *'As I said, it's a pity we hadn't a lot of that information three years ago. That was the biggest thing. It's brilliant now but it would make life easier for people if there was something like this earlier on.' (Caregiver C9, follow-up interview).*

The caregivers also felt better equipped to manage their self-care needs and avoid becoming 'burned out' by their caregiving responsibilities, by making time for their own interests:

> *'…Like I make time for myself now, you know. I was going to a gym and I was going in the evening time. Now what I'm doing is I'm going in the mornings. So by the time I get up and go - like this morning now I went - by the time I come back [the person I care for] is only starting his day … so it's not that he's missing out on anything or I'm missing out on anything and yet I've got the gym in… And I find I can go to the gym three times a week now' (Caregiver C2, follow-up interview).*

The positive feedback from the caregivers about the educational component of CREST highlights the importance of providing them with knowledge and coping strategies. Additionally, the emphasis on self-care highlights the need to support caregivers in managing their well-being to prevent burnout and maintain their caregiving capacity.

Volunteer older adults

The volunteer older adults reported improvements in their understanding and communication with people with dementia, suggesting that the intervention had a positive educational impact on them as well.

> *'We learned how to deal with people with dementia. How to approach them and understand you know someone else with dementia' (Older adult OA3).*

Whilst all the older adults agreed they were apprehensive before meeting the people with dementia, half of them stated they wouldn't have known initially that the people with dementia in the study had dementia and they expressed surprise at their level of understanding and ability to communicate.

> *'When I was paired with this girl I thought I'm the one has dementia, not her. She was so good. Only for the other two ladies told me about her you know I wouldn't have known in my meeting with her that she had it you know' (Older adult OA8).*

One volunteer commented that previously they would have been dismissive of a person with dementia and said they were a bit "*scattered*" [Older adult OA3] but now they would interact with them differently.

Three of the older adults felt that they were more patient, tolerant and sensitive towards people with dementia after participating in the exercise programme. Whilst another stated that taking part gave them a 'good feeling' as they had 'done something for somebody else' (Older adult OA4).

'Oh Yeah. We'd be far more tolerant of people and maybe sensitive' (Older adult OA1).

Discussion

The central tenet of dementia research states that the voices of people with dementia should be at the heart of such research [37], to amplify their preferences and direct research that is supportive of their needs, the needs of their families, and articulates both perspectives respectfully [38–40]. The CREST feasibility study aimed to capture these voices through qualitative interviews, highlighting the experiences of the people with dementia and their caregivers and also exploring the contributions of the volunteer older adults in supporting the intervention. By incorporating these perspectives using a qualitative approach, we provide a more comprehensive view of some of the components of the CREST programme's impact.

Interventions such as CREST, which are 'multicomponent', are valuable to people with dementia and their caregivers to promote their quality of life and management of dementia [41]. People living with dementia and their caregivers are at increased risk of experiencing social isolation [42]. The social aspect of the CREST intervention, whereby the people with dementia, their caregivers and the volunteer older adults could chat and communicate in a social way proved to be important for all groups. Attendance remained high throughout the intervention and while one person with dementia and their caregiver had to withdraw from the intervention within the first week due to illness, none of the remaining participants quit the programme. The people with dementia spoke positively about their participation in the CST and exercise components of the CREST intervention. Some of them described having better concentration and confidence and more motivation to take up new hobbies following their participation in the CST. This was corroborated by their caregivers. There has been consistent evidence for improved cognitive function from CST among people with dementia [17, 43] and while our study did not aim to investigate the effectiveness of the CREST intervention, anecdotal evidence suggests that the people with dementia benefited. Further research in the form of an RCT is needed to investigate this further. The people with dementia and the volunteer older adults also found participating in the exercise programme to be fun. Enjoying physical activity is an important motivator for engaging in exercise among people with dementia [44] and this may explain why some of the people with dementia and the older adults did not want the exercise programme to end.

While there can be positive aspects to caring for a person with dementia [45], caregiving can also be demanding both physically and psychologically [41]. Being a carer for someone with dementia can affect the carer's physical and mental health and their social relationships [40]. Caregivers can tend to sacrifice their own hobbies and social lives, which can lead to feelings of social isolation. Psychosocial interventions can have positive effects on the informal carers of people with dementia [46]. A systematic review and meta-analyses of RCTs found that interventions, which include teaching of coping strategies in combination with providing emotional support, are more effective for reducing carer burden [47]. Our research showed that caregivers liked receiving coping strategies that focused on how to communicate better with the person they cared for and also how to better manage their own self-care. Research has shown that caregivers who feel healthy and supported are better able to provide care for their loved ones with dementia [48]. In addition, they liked receiving knowledge about dementia.

Caregivers' levels of knowledge about dementia can play an important part in their resilience and ability to cope [49]. The caregivers appreciated that the education programme was delivered in a group setting. The effectiveness of interventions for caregivers is greater when delivered in a support group rather than individually [50] and caregivers regard support groups as an important source of connection with others who are experiencing similar circumstances [48, 49].

Volunteers are an important addition to dementia care [23, 51] and our study gives an example of how volunteers successfully supported people with dementia taking part in an exercise programme, motivating them to do the exercises and helping with social interaction within the group. Having the same volunteer/person with dementia grouping each week was also found to be important as it helped participants to get to know each other and to develop a rapport. Taraldsen et al. [22] described the importance of building relationships among adults with dementia and volunteers taking part in an exercise group. Previous research has found that volunteering can provide older adults with the opportunity to establish and maintain meaningful social relationships develop social skills and gain a sense of purpose.

Han & Brown [52] have suggested that older adults be encouraged to volunteer in activity-based social programmes for community dwelling people with dementia, because of the satisfaction and enjoyment they gained. Our study echoes these findings in that the older adults discussed feeling better equipped to communicate and deal with people with dementia, challenging initial stereotypes and reducing barriers between the groups.

The descriptive qualitative embedded study, conducted within this feasibility study, provided a rich understanding of participants' experiences of the exercise programme, the CST component and the caregivers' education component. The qualitative interviews revealed important aspects such as their motivation to participate in the CREST intervention, the significance of social connectedness and the perceived impact of the intervention on their lives. Similar to other studies [53, 54] embedding qualitative research within this feasibility trial facilitated the capture of valuable in-depth feedback which would otherwise have been missed. These insights can inform the future design and implementation of both CREST and other similar interventions.

Strengths and limitations

The people with dementia, their caregivers and the volunteer older adults reported their perceived changes after participating in the intervention. However, there was no objective measure of the impact. Participants' responses about the intervention may have been impacted by social desirability bias [55] whereby they gave favourable responses towards their experience of the intervention. In addition, the interviews were conducted by researchers familiar with the participants and while this may have enhanced openness it may also have introduced bias. In order to minimise this, interview guides were used and the researchers were trained to avoid asking leading questions. The ongoing data collection and analysis could have been perceived as burdensome by participants, however, none of the participants voiced any concerns about this and all engaged with each data collection point. This paper reported on the experience of using volunteer older adults supporting people with dementia in an exercise programme. The volunteers included almost equal numbers of men ($n=5$) and women ($n=4$) and previous research has identified the importance of including both in such interventions [56]. This study captured the people with dementia and their caregiver's experience of the CREST intervention and overall reported a positive experience. All participants, including the volunteer older adults, enjoyed the social engagement and described benefits from their participation. However, the overall findings are limited by a small number of participants and a full-scale RCT would help to further explore their experience of the CREST intervention and provide the opportunity to evaluate the impact of the intervention. Finally, the people with dementia in this study were living at home and had mild-moderate dementia and so further research is needed to see if the CREST intervention would work as well with people in a more advanced stage of dementia.

Conclusion

Participation in the CREST intervention produced a positive impact on all three groups: the people with dementia living at home, their caregivers and the volunteer older adults who supported the people with dementia in the physical exercise programme. The qualitative insights gained from this study provided a deeper understanding of the motivations and experiences of participants emphasising the importance of social connectedness and the perceived benefits of the CREST programme. These findings highlight the importance of embedding qualitative research within a feasibility study to gather detailed feedback that can inform future intervention design and implementation. Future research may now focus on a full-scale randomised controlled trial to evaluate the effectiveness of the CREST intervention and to explore its applicability to individuals with more advanced dementia. As the number of individuals living with dementia increases, creating innovative and evidence-based interventions that improve the well-being of both people with dementia and their caregivers is crucial.

Supplementary Information

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Supplementary Material 1.

Supplementary Material 2.

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Authors' contributions

D.C., S.S., P.D., N.G. conducted the individual and group interviews and D.C., S.S., P.D., G.OS. analysed and interpreted the data. B.W. drafted the manuscript. All authors contributed to the interpretation of the analysis and critically revised the manuscript. All authors read and approved the final manuscript.

Authors' information

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Availability of data and materials

The data that support the findings of this study are available from the corresponding author upon reasonable request.

Declarations

Ethics approval and consent to participate

Ethical approval for this research study was obtained from the University of Galway Research Ethics Committee (Ref: 16-Feb-03). Consent to participate was obtained from all participants.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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