Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Cefnogi pobl sydd â chyflyrau cronig

This response was submitted to the Health and Social Care Committee consultation on supporting people with chronic conditions.

CC07: Ymateb gan: | Response from:

Gwasanaeth Clefyd Cynhenid y Galon i Oedolion / Adult congenital heart disease Cardiff & Vale UHB (ACHD)

The South Wales ACHD pilot wellbeing group

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Background

People with CHD are at significantly increased risk of mental health difficulties (Jackson et al.,2020) and there are many factors that contribute to the social-psychological difficulties faced (Kovacs et al., 2022). Major illness or medical interventions in childhood can be understood as an adverse childhood experiences (O'Leary et al, 2022), and without necessary protective factors, the long-term impact of such experiences on both physical and mental health have been well documented (Hughes et al., 2017). Living with congenital heart disease in childhood disrupts normal developmental stages and can have a significant negative impact on educational attainment, the development of friendships and feelings of self-efficacy and hopefulness for the future (Kovacs et al, 2022). This has an impact on the beliefs and opportunities people experience in adulthood. Changes in health can further impact on this, and cause a huge bio-psycho-social burden including the burden of physical symptoms, economic impact, loss of roles and challenges in maintaining social connections. Loss of social contact and relationships can result in feelings of isolation and loneliness.

Psychological wellbeing and social connection are predictive of mortality and morbidity (Kovacs et al, 2022), with depression, anxiety and loneliness associated with an increased risk of death and of more severe disease. It is vital that we provide a biopsychosocial model of care and that people living with CHD have access to interventions aimed at improving social connection, self- efficacy and psychological wellbeing.

Here we describe a pilot project, in which we supported 10 people under the care of the ACHD team to attend a six session, once weekly, four-hour group based at the Orchard, in UHL. The group was facilitated by Down to Earth (funded by Cardiff and Vale Health Charity). Two members of staff (1 consultant clinical psychologist and 1 clinical nurse specialist) attended each session. Group-based interventions widen access to support and also offer participants the opportunity to develop peer relationships and to hear the experiences of others with similar conditions. Based outside, the group increased green access, which has been shown to improve mental health and wellbeing (Davies et al., 2019). We hoped that the group would improve wellbeing, social connection, self-confidence and also improve relationships between patients and healthcare workers.

Group

The nursing and psychology ACHD team identified patients who may benefit from the group. A clinical nurse specialist or clinical psychologist attended each session to support group members. The clinical psychologist rang each group members after both session 1 and 2 to discuss how the person was finding the group and to support them with any issues that had arisen. The psychologist also rang individual group members after subsequent sessions if additional discussions or reflections were required.

Two group members identified as male, 6 female and 1 as non-binary. Members ranged between 25 and 52 years of age. All participants had had previous surgery for a congenital heart condition. Three members were also under the care of the palliative (supportive) care team, including one member who was on the active waiting list for a heart transplant.

Six group members completed the Edinburgh Wellbeing Measure pre and post the completion of the group. Nine participants completed written feedback on their experience of the group.

Activities were tailored to individual need and ability. All activities focused on caring for the Orchard and developing outdoor skills. Activities included fence building, bird house making, wood preparation and tending to the Orchard.

Outcomes

No group members dropped out from the group. Minimum attendance in a session was 8/10 participants and maximum attendance was 10. Reasons for missing a session included sickness, transport difficulties (one member travelled from Brecon Beacons) and a pre-planned holiday.

Written feedback

	Strongly agree	Agree	neutral	disagree	Strongly disagree
Attending the group has helped me feel more connected to others	6	3			
I valued the opportunity to attend the group with others with ACHD	8	1			
Attending the group has had a positive impact on my relationship with my CHD team	8	1			
Attending the group has improved my wellbeing outside of the sessions	4	4	1		
I would be interested in attending another wellbeing group	7	2			
Attending the group has positively changed how I view my physical ability	4	2	2	1	
Attending the group has improved my fitness	1	3	6		

Table 1: responses from the written feedback based on likert style questions

All participants reported finding the group valuable (see Table 1). Benefits included building of peer support, improvement in relationships with healthcare team, and an increase in wellbeing.

Social connection

All participants felt the greatest impact was that of building peer support and connection. One group member "*We found that we all spoke the same 'language' almost and knew instinctively how to speak to each other about our conditions. I experienced a sense of true understanding for probably the first time in 30 years! Speaking to people who have had surgery and experienced the same tests, procedures and interventions has really lifted a lot of weight. I have been really fortunate to have made friends within this group and I already know that there will be a lot of conversations when we are attending hospital appointments and having other interventions to help us get each other through our experiences. For this I cannot thank you enough*", another explained ***"It has made me realise I am not alone, I felt valuable. It has been useful to hear other people's experiences and share my own".*** One member reported, ***"Bad health days make you feel less sociable and withdrawn. The sessions reminded me of the strength/power of time with others especially if you are having a bad day. Being open to***

making new connections and learning new skills will undoubtedly help my resilience as my health deteriorates. Group members also reported an improvement in social connection outside of the group ***"Spending time at The Orchard had a lovely impact on relationship with my wife. I left the sessions feeling connected and relaxed. This allowed the space emotionally to discuss with her the difficult topics of ill health, anger to our situation, and the uncertainty it brings as we drove home. Death is never an easy topic to discuss with a loved one".***

All members felt that the group had improved their relationship with their healthcare team and that this would be helpful in managing their health condition ***"I feel that this relationship with the team has the potential to reduce stress and anxiety when attending appointments, knowing that these people who you 'know' and are familiar with are going to be there. It could also make it easier when times are tough and there may be some bad news that needs to be heard, it's a lot easier to hear this from someone you know a bit better and can be open and honest with."***

Wellbeing

Participant no	Pre group assessment	Post group assessment
1	59	65
2	53	65
3	40	40
4	47	52
5	40	50
6	29	46
Mean	44.67	53

Table 2: Edinburgh Wellbeing Measure pre and post group

Six group members completed the Edinburgh Wellbeing Measure pre and post the group (see Table 2). Of these, 5 showed improvements in wellbeing and 1 showed no change despite having a significant negative life event occur in session 3. The measure's score can range between 14-70. A score of below 42 indicates a person is in the bottom 15 percent for wellbeing and a score below 40 identifies a person as high risk of depression.

In support of these findings 8/9 participants reported an improvement in their wellbeing and the patient for whom there was no change reported "***I don't know where I would be without the group".*** Behavioural activities during the sessions enabled the psychologist to reinforce and explore shifts in cognitions. Written feedback demonstrates significant shifts in cognition and behaviour relating to self-confidence and self-efficacy with one member explaining "***the others I have met and what I have achieved has been a source of encouragement and more of a 'I can' attitude. I think it is something I need to work on proactively outside of the sessions but I need to look back and reflect and remind myself of everything we achieved".*** Another member reported "***I always felt so much better mentally and emotionally when attending. Learning new skills in a beautiful setting was restorative. I had not expected to feel so uplifted".*** In line with psychological models which focus on the importance of having meaning and value in our living, patients reported enjoying knowing they were contributing to the upkeep of the meadow ***"By supporting the development of the wildlife meadow, I have also felt connected to anyone who may use that facility in the future including others with health conditions,***

hospital inpatients, staff and the wider community". This also supports research that shows the benefits of "green access" for our wellbeing.

Participants were asked to describe how they felt after each session. Reponses included: Peaceful, more at ease, better about myself, happy, weightless, tired but in a good way.

Fitness

Nearly half felt that the group had a positive impact on their fitness, both directly by engaging in physical activities, and indirectly, by changing perceptions and behaviours relating to fitness outside of the sessions. Written, additional feedback showed that one person explained that they had started coming to the sessions early to exercise outside, and another reported that previously been afraid to walk anywhere and that they always wanted to know where the closest defibrillator was. Since attending the group, they had joined a yoga class and were contemplating doing a couch to 5k programme. Another participant had found ways to walk with her family when they would previously have gone home.

Discussion

Here we discuss the outcomes and experiences of 10 people with CHD who attended an outdoor, group-based wellbeing programme. Attendance was excellent and all participants reported finding the group beneficial. Benefits included improved social connection, the development of peer relationships, increased fitness, changes in beliefs and behaviours relating to self-efficacy and confidence and improved relationships with their healthcare team. Group members plan to continue to support each other now that the pilot has ended and have set up a group "whatsapp". The HCPs who attended the group reported improved wellbeing and having found the group enjoyable and beneficial for patients.

Recommendations and future activity

- This pilot shows the positive impact a group based-outdoor group can have on the physical and psychological wellbeing of people living with congenital heart disease
- Patients report finding peer support to be extremely beneficial
- The positive outcomes highlight the need for further group-based activities and for access for peer support
- We plan to run a second group, with some original members invited back to participate in a peer mentor training programme.

References

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