

A Multimethod International Mapping Exercise of Arts Interventions in Renal Units: The PAINT Project

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Keywords

Kidney disease · Quality of life · Arts · Qualitative interviews · Health and well-being

Abstract

Introduction: Due to the chronic nature of kidney disease, the challenges of symptom burden, and reduced mortality and comorbidity, individuals living with the condition experience substantial anxiety and depression. Incorporating the arts into clinical practice is encouraged to promote and support mental health and well-being. The aim of the PAINT project was to undertake an international mapping exercise to identify the current provision of arts programmes in kidney centres for people living with kidney disease. **Methods:** A multimethod approach was employed, involving a cross-sectional online survey and semi-structured qualitative interviews, which employed qualitative description research design. Healthcare staff working in kidney centres or organisations providing arts activities to individuals living with kidney disease were recruited into the study. **Results:** One hundred and

nineteen participants from 29 countries responded to the survey, with 39 of the respondents reporting arts activities in their renal unit. There was a wide range of respondents in terms of role, and the types of arts activities included visual arts activities, music, literature/creative writing, film, movement/dance, and craft. Individuals with chronic kidney disease who had taken part in arts activities were mostly adults (64%), and most were undergoing haemodialysis (82%). Sixteen respondents participated in the semi-structured interviews and encouraged the adoption of arts activities for people living with kidney disease. Three themes were identified: enhanced well-being and positive outcomes for individuals living with kidney disease; staff engagement and enthusiasm; and barriers to participation. **Conclusions:** This overview of arts activities being offered globally to people living with kidney disease and experiences of renal healthcare staff who provide activities in their units are encouraging in terms of arts in healthcare. These practitioners have observed the benefits of this person-centred arts approach in action, predominantly in terms of the positive impact on the well-being of individuals with kidney disease and improved

relationships with staff in dialysis units. Further attention and funding should be focused on arts activities within renal centres.

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Introduction

Individuals living with chronic kidney disease (CKD) experience challenging physical and psychological symptoms that lead to lower levels of health-related quality of life than the general population [1]. Due to the chronic nature of kidney disease, individuals experience high levels of anxiety, with some estimates indicating a greater than 50% prevalence rate [2]. Depression and anxiety are the most common psychiatric disorders with depression affecting up to one-quarter of this population [3]. The high prevalence rates of depression and anxiety compared to other chronic diseases are an important concern [4]. In addition, many people living with CKD require haemodialysis, which involves attending hospital three times a week for 4 h each visit and there exists a high burden of haemodialysis on the mental health and quality of life of individuals living with CKD [5].

The use of the arts to promote and support health and well-being has received ongoing attention since the publication of the World Health Organisation 2019 report, which highlights the evidence for arts in benefitting health and well-being for people living with chronic illness [6]. This person-centred approach to patient care has been examined previously with populations in various healthcare settings, including older individuals in acute settings [7], hospital-based patients post-stroke [8], and people with dementia [9]. Less is known about the use of the arts to benefit those living with CKD.

The Renal Arts Group (RAG) is a collaborative research group established in 2016 at Queen's University Belfast [10] between individuals living with CKD, carers, clinicians, academics, and artists. RAG's ethos is to develop a programme of research aimed at improving the physical and psychological quality of life of those living with CKD through the medium of art. The formation of RAG has provided opportunities for multidisciplinary education and research which has extended to an international audience [11, 12]. A realist synthesis [5] conducted by the team acknowledged a dearth of literature around kidney disease and the arts, and identified a need for randomised controlled trials to explore the effectiveness of complex arts-based inter-

ventions for people receiving haemodialysis. Subsequently, an art-based intervention was developed and implemented with individuals during their haemodialysis sessions [13, 14]. Results indicated that participants found the arts more accessible and enjoyable than anticipated and benefits suggested improvements in mental well-being. Little is known about the use of arts activities for individuals with CKD globally. The PAINT project, a multimethod international mapping exercise of arts interventions in renal units, aimed to identify the current provision of arts programmes for individuals living with CKD. The project was co-produced with a consortium made up of members of RAG in partnership with arts programmes based in the Philippines, USA, Ireland, and at the World Health Organisation.

Research Aims

The aims of the current study were as follows:

1. To identify current provision of arts activities available for individuals with CKD internationally and
2. To explore the experiences of renal healthcare staff and arts coordinators who provide activities in renal units.

Research Approach and Methodology

Design

A multimethod approach was employed, including a cross-sectional online survey and semi-structured qualitative interviews. The research design qualitative description was adopted for the interview element of the study, which focuses on the direct and rich description of experiences or events, and maintains a close proximity to the data without straying into extensive theorisation [15–17]. Qualitative description is appropriate in multimethod research to obtain first-hand knowledge of patients, relatives, or professional experiences [17]. The interviews were used to gain deeper insights into participants' experiences of the arts interventions reported in the survey, as part of the overarching exploratory sequential design of the study. Multimethod has been defined and distinguished from mixed methods, as the practice of employing two or more different methods or styles of research within the same study or research program rather than confining the research to the use of a single method [18, 19]. Multimethod research differs from that of mixed methods; in that, it is not restricted to combining qualitative and quantitative methods but rather is open

to the full variety of possible methodological combinations [20] (p. 187).

The cross-sectional survey aimed to map provision of arts activities for individuals living with CKD and gather information about the implementation of these activities including how they were received by these individuals (online suppl. Appendix I; for all online suppl. material, see <https://doi.org/10.1159/000542878>). The survey was pilot-tested by distributing it initially to project partners. Their input and feedback were taken on board in the final version of the survey, which was then disseminated more widely.

The Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklist has been used to report on the cross-sectional survey aspect of this study (online suppl. Appendix II) [21]. The interview schedule (online suppl. Appendix III) was developed, to further explore the delivery of arts activities, using the RE-AIM QuEST framework [22], which is a planning and evaluation framework. The RE-AIM framework outlines that the reach, effectiveness, adoption, implementation, and maintenance of an intervention should be explored with both qualitative and quantitative measures, to enable the identification of any necessary modifications to replicate in future research and translate into clinical practice [22, 23]. The consolidated criteria for reporting qualitative research (COREQ) checklist has been used to report the qualitative component of the study (online suppl. Appendix IV) [24].

Recruitment

Healthcare staff working in renal units, health centres, or organisations providing arts activities to people living with CKD were recruited into the study. Individuals were invited to respond to the PAINT survey whether arts activities were being offered in their unit or not, as it was hoped to understand the reasons why arts activities were not being offered. The participant information sheet, consent form, and survey were available on a webpage on the RAG website. A link to the website was shared with renal units identified through RAG's established connections with renal and healthcare networks, including the European Dialysis and Transplant Nurses Association/European Renal Care Association (EDTNA/ERCA), the Association of Nephrology Nurses, Kidney Care UK, the Renal Society of Australasia, and the International Society of Nephrology, all of whom subsequently cascaded the information to their networks, along with support from our project partners in their respective regions.

In terms of sample size for the survey, it was not possible to accurately determine the number of renal units worldwide to base a sample size calculation. A target sample size of 100 was thought to be a reasonable estimate, and so was aimed for and exceeded.

Participants were asked to confirm that they met the inclusion criteria for the study before they completed the survey. Any member of healthcare staff working in a renal unit, healthcare centre, or organisation providing arts activities to individuals living with CKD was eligible for inclusion. There may have been more than one response from the same unit, hospital, or organisation, but various perspectives were welcomed.

When completing the survey, participants were asked to indicate if they consented to take part in a follow-up interview. Prospective interviewees were subsequently invited by email using purposive sampling, with the aim of including a range of roles and centres taking into account type of arts activity, patient groups involved and geographical distribution. The research team invited participants from various centres/units to take part in a qualitative interview at a time that suited them. Survey respondents were invited to interview whether they did or did not offer arts activities, in order to more fully understand aspects such as barriers to participation in the arts activities for individuals living with CKD.

In terms of sample size for the interviews, there are no definitive guidelines to determine the ideal sample size in qualitative research [25]. Hennink and Kaiser's [26] systematic review suggests that a sample size between 9 and 17 interviews can be appropriate for data saturation. Data saturation refers to the point in the research process when no new information or insights are discovered, therefore indicating to the researcher that data collection may cease [27]. The study aimed to recruit 10 participants; however, recruitment continued until the researchers deemed data saturation had been met and 16 interviews were completed.

Data Collection

The survey was hosted online using the Qualtrics software [28] and was embedded into the RAG website, and the link to the webpage was circulated electronically via email or social media. The majority of recruitment was therefore based on voluntary visits to the Qualtrics website. The survey was active from January to November 2023 and took approximately 10 min to complete. The Qualtrics software was able to detect that 268 people clicked on the link to the survey. Seventy-four participants responded to the survey using the Qualtrics link. It

may therefore be deduced that 114 people clicked on the link and opted out of completing the survey. Missing data was not a factor for participants who completed the survey, as in Qualtrics “response requirements” were placed on each of the items, so that respondents were unable to skip out items.

Hard copies of the PAINT survey were made available to delegates of the EDTNA/ERCA Congress in October 2023. Further 45 respondents were recruited in this way.

Primarily, the survey aimed to capture the availability of arts activities to those receiving treatment in the unit in which the respondent was working or had been available in the past. If they had, the respondent was subsequently asked, in a series of closed items, about the following variables: the types of arts activities made available; the types of patients who took part in the activities (e.g., children/adults/patients undergoing haemodialysis/patients undergoing peritoneal dialysis, etc.); number of patients having participated in the arts activities in the last 12 months; reasons for their organisation offering arts activities; numbers of patients participating in activities and with what frequency; and the basis on which the activities were offered (i.e., one-off/on a short-term basis/on a long-term basis). The full set of items may be seen in online supplementary Appendix I PAINT Survey.

More explorative, open-ended questions were posed towards the end of the survey regarding the way in which the arts activities were promoted, how they were funded, whether any arts-based research had been published, and any other information the respondent wished to share. Survey participants were asked to indicate if they would be willing to take part in a follow-up interview. Fifty-five of the 119 respondents were willing to be contacted about an interview. Prospective interviewees were approached directly via email by the researcher. Purposive sampling was adopted to ensure a spread of geographical regions and professional experience of interviewees.

The interviews took approximately 30 min to complete and were undertaken between July and November 2023 on Microsoft Teams by the postdoctoral research fellow (TF) who is experienced in conducting qualitative interviews. Participant knowledge of the interviewer was limited although participants had some knowledge of the researcher’s research interest and why the researcher felt the study was important. No repeat interviews or field notes were undertaken, and interview transcripts were not returned to participants prior to data analysis.

The interviews were semi-structured, and 15 of the 16 interviewees had worked in renal units where at least

some level of arts activities had taken place. This majority of interviews explored the arts interventions within the unit in terms of their content, level of involvement of individuals with CKD, how often the arts activities took place, where and how they were delivered and by whom. The potential impact on individuals with CKD, staff, and facilitators was also explored in the interviews, as well as barriers to providing the arts activities and plans for further arts-based interventions. For the remaining interview, arts activities had not taken place in the renal unit in which this participant worked. On this occasion, the line of questioning of the interview was around why arts activities had not taken place, the barriers, and the potential impact arts activities might have should they take place in the future. The semi-structured interviews were conducted, audio recorded, and transcribed verbatim by the research fellow (TF) and reviewed by the principal investigator (HN). The interviewer was an active member of RAG with an interest in and knowledge of arts and health research. Participant data were pseudo-anonymised prior to review and analysis by the wider research team.

Data Analysis

Data were extracted from the survey results to identify the provision of arts interventions that are currently available in renal units, to include the range of activities, groups of individuals with CKD involved, and delivery of interventions. This included demographic information about the respondent and their centre/unit, quantitative data in response to categorical and/or dichotomous items, and qualitative responses to open-ended questions.

The qualitative interview data were input into NVivo v.12 software [29], and common codes and themes were identified. Data were analysed using Braun and Clarke’s [30] six stages of thematic analysis by members of the research team (TF and AW) led by the chief investigator (HN). Transcripts were coded by two researchers with the necessary experience in the field, including an experienced qualitative postdoctoral researcher and research assistant/PhD student with extensive qualitative experience and in-depth knowledge of the subject matter. H.N., A.W., and T.F. were involved in cross-checking the results, and disagreements were resolved through discussion. Analysis included familiarisation with the data; generating initial codes; searching for themes; reviewing themes; defining and naming themes; and producing the report. An inductive approach was taken to the analysis, which refers to the development and modification of codes throughout the coding process. Data saturation was achieved after 13 interviews with 16 interviewees; most of

Table 1. Geographical spread of survey respondents/interviewees and the frequency (and percentage) of those respondents who offer or have offered arts activities to individuals living with CKD in their unit

Country	Respondents, n = 119 (%)	Respondents who provide/have provided arts activities, n = 39 (%)	Respondents who do not provide arts activities, n = 80 (%)
England	35 (29.4%)	10 (25.6%)	25 (31.3%)
The Philippines	14 (11.8%)	11 (28.2%)	3 (3.8%)
Denmark	7 (5.9%)	2 (5.1%)	5 (6.3%)
Northern Ireland	6 (5%)	2 (5.1%)	4 (5%)
Canada	6 (5%)	1 (2.6%)	5 (6.3%)
Republic of Ireland	6 (5%)	4 (10.3%)	2
Lithuania	4 (3.4%)	1 (2.6%)	3
Scotland	3 (2.5%)	2 (5.1%)	1
Iceland	3 (2.5%)	0	3
Greece	3 (2.5%)	0	3
Germany	2 (1.7%)	0	2
Wales	2 (1.7%)	0	2
India	2 (1.7%)	1 (2.6%)	1
Italy	2 (1.7%)	0	2
The Netherlands	2 (1.7%)	0	2
Slovenia	2 (1.7%)	0	2
Belgium	2 (1.7%)	0	2
Saudi Arabia	2 (1.7%)	1 (2.6%)	1
Turkey	2 (1.7%)	1 (2.6%)	1
Greece	2 (1.7%)	0	2
Croatia	2 (1.7%)	1 (2.6%)	1
Nigeria	1 (0.8%)	1 (2.6%)	0
Pakistan	1 (0.8%)	0	1
United States of America	1 (0.8%)	1 (2.6%)	0
Vietnam	1 (0.8%)	0	1
Austria	1 (0.8%)	0	1
Spain	1 (0.8%)	0	1
Holland	1 (0.8%)	0	1
Bosnia and Herzegovina	1 (0.8%)	0	1
Sweden	1 (0.8%)	0	1
Unknown	1 (0.8%)	0	1
Total	119	39	80

the interviews were one-to-one, but one of the interviews was a dyad and one was a triad, largely due to language barriers. Member checking was not undertaken as the research team did not wish to cause additional burden to the participants.

Ethical Considerations

Ethical approval was granted by Queen's University Belfast Faculty Research Ethics Committee (REC Reference Number: MHLS 22_138) prior to the commencement of the PAINT study.

Table 2. Roles of PAINT survey respondents

Role	Respondents, <i>n</i> = 119 (%)
Registered nurse	47 (39.5%)
Nephrologist/nephrologist fellow	29 (24.4%)
Arts manager/coordinator/director	12 (10.1%)
Doctor/physician	10 (8.4%)
Researcher/lecturer	4 (3.4%)
Renal dietician	3 (2.5%)
Renal counsellor	2 (1.7%)
Renal social worker	2 (1.7%)
Other (e.g., occupational therapist, clinical educator, dialysis manager, etc.)	10 (8.4%)
Total	119

Results

Geographical Spread

One hundred nineteen participants responded to the PAINT survey between 18 January and 3 November 2023. In terms of the geographical spread of respondents, 29 countries were represented. The largest proportion of respondents was from England (35 of the 119 participants, 29.4%) as can be seen in Table 1. While 14 of the participants were from the Philippines, 13 of the 14 were from the same hospital. Table 1 details the frequency of survey participants from other countries as well as the number of respondents who offer arts activities or have offered arts activities in the past.

Participant Roles

Professional roles of survey respondents are summarised in Table 2. The largest proportion of respondents were registered nurses ($n = 47$, 39.5%). The second largest professional group were consultant nephrologists ($n = 20$, 16.8%), and 12 of the 119 respondents (10%) were from an arts background.

Arts Activities

Survey respondents were asked whether or not arts activities were available to people living with CKD in their unit, or whether they had been available in the past. The results are shown in Figure 1.

Individuals with CKD who had taken part in arts activities were mostly adults (25 of 39 respondents, 64%), and most were undergoing haemodialysis (32 of 39 respondents, 82%). The most frequently cited reasons for

offering arts activities were to benefit individuals living with CKD (34 of 39 respondents, 87%); to benefit the families of those living with CKD (16 of 39 respondents, 41%); to enhance public/community health (14 of 39 respondents, 36%); and to expand outreach or community engagement (13 of 39 respondents, 33%). The majority of respondents (26 of 39 respondents, 67%) indicated that less than 25 individuals living with CKD had participated in arts activities in their unit in the last 12 months, although 3 respondents (8%) said that over 100 individuals had taken part.

There was a range of responses to the question regarding how frequently individuals participated in arts activities: 11 of the 39 respondents (28%) indicated that the individuals living with CKD took part weekly, while another 11 respondents (28%) reported frequency of participation less often than monthly. The arts activities were usually offered as a one-off (12 of 39 respondents, 31%) or on a short-term basis (11 of 39 respondents, 28%). Twenty-one of the 39 respondents (54%) indicated that the arts activities were still active in their unit at the time of responding to the survey.

In terms of location, 28 of the 39 respondents (72%) indicated that the arts activities were available in a clinical setting while individuals were on dialysis. Eight respondents (20.5%) said that arts activities were offered in another internal location within the renal unit/health centre/hospital, while 5 respondents (13%) indicated that the arts activities were facilitated in an external location, usually at the individuals' homes.

In terms of the number and roles of personnel who were involved in delivering the arts activities to individuals

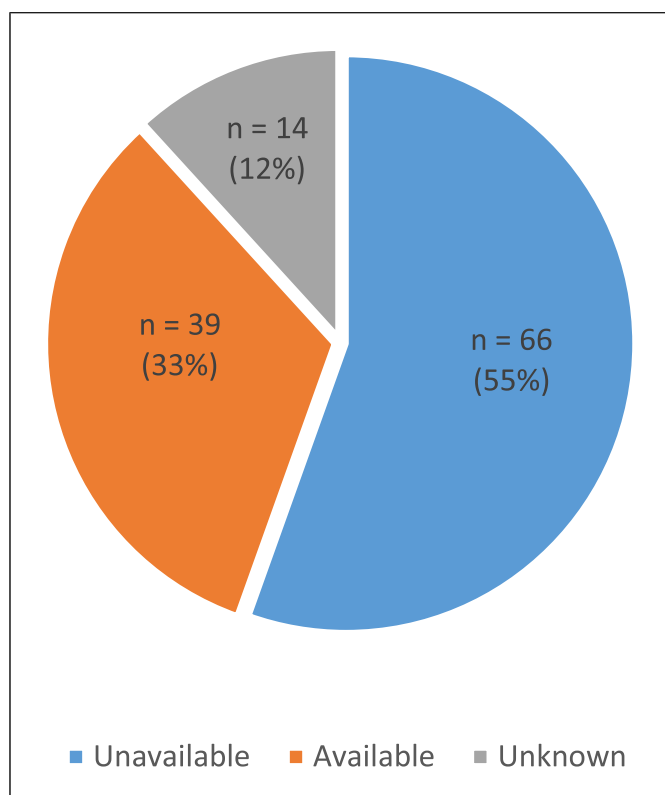


Fig. 1. Frequency ($n = 119$) of respondents who indicated whether or not arts activities were available in their unit or had been available in the past.

living with CKD, 2 of the respondents (5%) indicated that their programmes relied heavily on volunteers while another three respondents (8%) relied on the help of students to deliver their arts activities. There was a wide range of arts activities offered. The 39 respondents who provided arts activities, or had done in the past, were asked to indicate from a list which types of arts activities they provided; respondents were invited to tick all that applied. The most frequently reported arts activity provided was visual art, with 27 of the 39 (69.2%) indicating that visual arts activities were provided to individuals in their renal unit or had been provided in the past. Twenty-four respondents (61.5%) said that music had been provided as an art activity within the renal unit that they worked in. The full breakdown of results to this item is shown in Table 3.

Qualitative Demographic Information

In terms of the demographics of the interviewees, thirteen qualitative interviews were conducted online on Microsoft Teams with 16 participants representing 11 countries, as shown in Table 4. The interviewees were

labelled according to their role and numbered chronologically to distinguish between them when reporting on the qualitative data. Table 4 also displays the countries where the interviewees were based, as well as the interviewees' gender (81% were female and 19% were male).

Most of the interviews took place on a one-to-one basis, but due to language barriers, two of the interviews took place as a dyad or triad – i.e., the participants from Saudi Arabia and Turkey, respectively; hence, 13 interviews were conducted with 16 participants. One of the interviewees did not offer arts activities in their renal unit, while the other 15 interviewees had at least some experience of being involved in arts activities in this context.

Qualitative Themes

In this section, data gathered from the qualitative, semi-structured interviews will be discussed. Themes and sub-themes identified from the qualitative data are shown in Table 5.

1. Enhanced Well-Being and Positive Outcomes for Individuals Living with CKD

When asked how individuals responded to arts activities, all of the interviewees discussed benefits of the arts for people with CKD. The positive impact that engaging in the arts had on individuals' mood was discussed, including the idea that individuals with CKD were rediscovering their sense of purpose. It was suggested that some people who engaged in arts activities while on dialysis were now looking forward to their dialysis sessions and were glad to have the opportunity to share their interest in their chosen art form. One interviewee emphasised how individuals engaging in arts activities tended to feel "calmer," and reported that family members of those on dialysis were able to vouch for this impact:

[Individuals engaged in arts activities] *were more positive, they were happier to come to dialysis and they had a smile on their faces, something that I had not seen before, and it was a big impact and we heard this a lot from their families as well. When we had the exhibition there was enough room that families were able to come along. And they would chat to us and say they couldn't believe the effect it had on them, that they've got a sense of purpose again and a feeling that their life isn't over, that there are things they can do, that sort of thing. So yeah, a lot of positivity.* [Consultant nephrologist 2]

Interviewees emphasised how arts activities tended to keep individuals more mentally stimulated and socially engaged while on dialysis, in an otherwise highly restrictive

Table 3. Frequency and percentage of respondents who indicated that they provided various types of arts activities to individuals living with CKD

Type of art activity	Frequency of respondents, n = 39 (%)
Visual art	27 (69.2%)
Music	24 (61.5%)
Multidisciplinary (e.g., music and visual art)	5 (12.8%)
Literature/creative writing	5 (12.8%)
Film	5 (12.8%)
Movement/dance	4 (10.3%)
Craft	4 (10.3%)
Drama	1 (2.6%)

Respondents were invited to “tick all that apply” in response to this item; therefore while there were 39 respondents, there were more than 39 responses.

Table 4. Demographic characteristics of interviewees

Interviewee	Country	Gender
Counsellor 1	N. Ireland	F
Consultant nephrologist 1	Scotland	M
Arts coordinator 1	USA	F
Consultant nephrologist 2	The Philippines	F
Nephrology fellow 1	The Philippines	F
Nephrology fellow 2	The Philippines	F
Arts coordinator 2	Republic of Ireland	F
Consultant nephrologist 3	India	M
Nurse 1	Slovenia	F
Consultant nephrologist 4	England	M
Nurse 2	Saudi Arabia	F
Dietician 1	Saudi Arabia	F
Nurse 3	Denmark	F
Academic 1	Turkey	F
Academic 2	Turkey	F
Academic 3	Turkey	F

Participants were pseudonymised to their profession and a number.

situation. The fact that some individuals started to “look forward” to dialysis was discussed, and it was felt having the arts activities to look forward to enhanced individuals’ motivation and enthusiasm.

1.1 Reduced Boredom and Constructive Use of Time

Interviewees reported that arts activities helped reduce individuals’ levels of boredom while on dialysis and helped time to pass more quickly. There was an overriding desire from individuals to be able to do something constructive while on dialysis. This counsellor described how people were keen to know when the opportunity to participate in further arts programmes would arise:

Some still say to me about [the arts programme], “When are we doing more of that?” So some of the people were just really engaged with it and really enjoyed it. They felt that the time went so much quicker and they were looking forward to the people coming in. [Counsellor 1]

Individuals with CKD felt that the use of arts activities led to a feeling that they were using their time on dialysis constructively and that they were “glad of the opportunity to ‘occupy the mind’ in a meaningful way” [Arts Coordinator 2]. One of the interviewees described how the arts activities which took place in their unit prevented boredom among the individuals on dialysis and helped provide them with more of a focus and a type of incentive to stay on dialysis:

How this activity is keeping them more active and also enthusiastic to continue their dialysis and not getting bored and not demanding too much because they have something that they are working on, a focus. [Nurse 4]

1.2 Legacies of Individuals Living with CKD

The artwork of individuals living with CKD produced during dialysis had an important part to play in creating legacies. Arts coordinators discussed how they often worked with older individuals on dialysis units, and survival rates were not high. These interviewees expressed

Table 5. Themes and sub-themes identified from the qualitative interview data

1 Enhanced well-being and positive outcomes for individuals living with CKD	2 Staff engagement and enthusiasm	3 Barriers to participation
1.1 Reduced boredom and constructive use of time	2.1 Staff observing positive outcomes for individuals living with CKD	3.1 Resources – funding and staffing
1.2 Legacies of individuals with CKD	2.2 Staff participation in the activities	3.2 Infection control, logistics of being on dialysis, and patient fatigue
	2.3 Relationship development	3.3 LMIC are “surviving rather than thriving”
LMIC, low- and middle-income countries.		

a hope that creating something with individuals might provide comfort to family members, as illustrated by this quote:

We’ve lost a lot of patients over the years as well. You know, they’re chronically ill. That’s why they’re on dialysis (...) but like looking back and that kind of thinking about what they created and families having the comfort that they have this thing that, or a book or something, that you know that it helps them remember the person which is really, really lovely as well. [Arts Coordinator 2]

One of the interviewees emphasised how the art work not only provided a legacy for individuals who had passed away, but also those who had received successful transplants:

Also, we just moved our dialysis unit and in the old dialysis unit, every patient had a ceiling tile painted. You know the drop ceilings and it was a really nice legacy for patients that had gotten successful transplants, patients that passed away, current patients, it was really nice. [Arts Coordinator 1]

2. Staff Engagement and Enthusiasm

2.1 Staff Observing Positive Outcomes for Individuals Living with CKD

Staff emphasised how they have observed a positive change in the atmosphere and mood of the dialysis unit when arts activities are introduced. Sometimes, this was described as a noticeable, physical change, such as lights in the rooms being on and people being upright and more alert. Other interviewees described how the mood and energy in the dialysis unit changed:

... just to lighten the mood of the whole thing as well so there was a bit of va voom going on, there was energy, there was something different. Because sometimes it can feel a very sleepy place basically, and a very clinical place, with all the alarms going off, so I think people really enjoyed it. And you can see that the mood for those who took part, but also for their neighbours. So

sometimes there were people who didn’t take part, but they were curious about what so and so was doing as well. So there was a wee bit more interaction between people. That was good. [Counsellor 1]

2.2 Staff Participation in the Activities

The vast majority of survey respondents who indicated that arts activities were available in their units also commented on how healthcare staff were receptive to these activities, and seemed to enjoy the arts activities as much as the individuals living with CKD. One interviewee indicated that arts activities in dialysis units were a highlight of the week for staff. An arts coordinator who came into the dialysis unit to facilitate activities described how staff “cheer their patients on” and are highly attentive to the needs of the individual in making participation in the activities possible. Staff enjoyed participating in the arts activities themselves, where possible:

Staff willingly offer their feedback and responses to the arts activities; Staff often join in/take an interest in what the patient is doing, and it offers them a new insight into the patient; Staff enjoy the live music on the dialysis unit as a welcome break and lift in the atmosphere. [Arts Coordinator 2]

2.3 Relationship Development

There was evidence within the qualitative data that the arts activities had the effect of enhancing relationships between individuals living with CKD and staff. Engaging in arts activities and producing artwork gave the staff and individuals with CKD something to discuss together. This quote in particular describes how the interaction between staff and individuals living with CKD on the renal unit served to humanise the relationship between the two:

The staff start seeing patients not just as patients and the patients they see them as humans and ... not that they didn’t before but you know that they’re really getting to know their patients in a new way that the arts can really do that and bring that to the situation. [Arts Coordinator 2]

3. Barriers to Participation

3.1 Resources: Funding and Staffing

The most frequently cited reason for arts activities not being available was a lack of resources including funding for material or staff resources to drive the programme of activities forward. In terms of staffing resources, one of the interviewees elaborated the following:

The main barrier is somebody organising it, to be honest. (...) It's the having someone to oversee it and to organise it and to have it running. I would love to have it running on a continual basis and we're looking at that and how we do that, but we're still at that point of who manages that, you know? [Counsellor 1]

One interviewee felt that a major barrier in terms of being able to resource the staffing for the facilitation of arts activities was overcoming this issue around “red tape.” He explained how, in the hospital he worked in, they had tried to engage volunteers from a local art club to facilitate the activities in the dialysis unit, but had come up against insurmountable problems:

And then we could not deliver it because we couldn't get through the red tape that was required. But the NHS regards them [volunteers from a local art club] as murdering criminals until proven otherwise. (...) So they've got to go through all sorts of hoops in relation to former criminality checks. (...) They're just, these highly, highly motivated people who were really keen to do something just ended up not happening because of so much red tape. [Consultant nephrologist 1]

Some participants felt that physical health was given priority over their mental health and well-being. One interviewee believed that funding would be acquired only if the arts activity showed a small positive change in the physical health measures of individuals, rather than their mental or emotional health and well-being:

And I was thinking if it was a brand new type of dialysis machine that showed a tiny improvement in blood haemoglobin levels, you know, somehow funding would be found for that. It might be a struggle, but this sort of thing, it seems to me, it would always come to the bottom of the pile. And yet we're always going on about trying to provide patient-centred care, about it's what matters to the patient that matters the most, not the haemoglobin, not the numbers. [Consultant nephrologist 1]

3.2 Infection Control, Logistics of Being on Dialysis, and Fatigue

For some interviewees, infection control was a hurdle to overcome in terms of facilitating arts activities in dialysis units. Infection control is of paramount importance in the dialysis environment where individuals with kidney disease are immunocompromised. This was a particular problem in the aftermath of the COVID pandemic, as illustrated by this quote:

We really struggled getting back into the hospital during and after COVID. And then I suppose the renal patients are kind of immunocompromised and you know, they were really looking after the patients and we had to make a really strong case to get back there. [Arts Coordinator 2]

The logistics of being attached to a dialysis machine at times did not lend themselves to individuals literally being in a good position to engage in certain activities. The infrastructure and ergonomics of the dialysis set-up were often the barriers. In addition, being physically attached to a fistula was problematic at times:

And the other big one that we had to adjust was what could we actually do when you had a fistula in, and, what could you do, and what if it was in your dominant arm, how were we going to get around that. [Counsellor 1]

Arts activities had to be modulated according to energy levels or fatigue. One participant highlighted their approach in this scenario when the individual might be too tired to participate in an arts activity while on dialysis:

Patients who are tired, or dealing with psychological stress may find art to be “too much” during dialysis. In these circumstances, I say a quick hello each week, and only offer art occasionally on what appear to be “good days.” Sometimes in these cases, I draw for the patient or deliver a ‘to go’ art kit.” [Arts Coordinator 1]

3.3 Low- and Middle-Income Countries: Emphasis on “Surviving Rather than Thriving”

There were some economic variations in terms of responses to the question regarding barriers to participation in arts activities. A respondent from the Philippines felt that “art appreciation is not widespread” in their country and that “people are surviving rather than thriving.” In low- and middle-income countries, such as the Philippines, the focus is on staying alive and more basic factors such as the medication and equipment required to do so. An interviewee from the Philippines expands on this in the quote below:

I would say a lot of the population are just struggling to survive day by day so they really cannot appreciate other things, other than the work that they have to do to be able to provide for their family. So it's unlike more progressive countries or the developed countries where the quality of life is really good. So there, they have time to indulge with other things like art or reading. Here it's just a matter of survival for the majority of the people. [Consultant nephrologist 2]

The respondent from Pakistan highlighted how dialysis is not fully supported and funded by the government and health department, and their dialysis unit had previously been run by technicians only; therefore, additional resources would be required for implementing arts activities and an out-of-reach aspiration.

Discussion

This study aimed to identify and explore the current provision of arts programmes for individuals living with CKD internationally. One hundred and nineteen survey respondents and interviews with 16 of these participants have provided an insight into the arts activities that take place in renal units in various countries around the world and the perceived impact they have on their well-being.

There is increased awareness of the positive impact that the arts can have on individuals' health and well-being since the publication of some key documents. In particular, the World Health Organization's extensive review of the literature [6] in 2019 highlighted the expansive and growing evidence base for the role that the arts have to play in the improvement of health and well-being. Since then, the National Centre for Creative Health and the All-Party Parliamentary Group on Arts, Health and Wellbeing's Creative Health Review: How Policy Can Embrace Creative Health [31] highlights the potential for creative health to help challenge the major issues facing health and social care. One of the key messages to emanate from this review is that creative health should form an integral part of the health and social care system moving forward and that this system would subsequently be more holistic and person-centred. Findings from the current study support this proposal, with one of the key themes resulting from the qualitative data being around the impact of arts activities being enhanced well-being of individuals living with kidney disease.

Similar to the outcomes of a small number of previous studies, the themes and sub-themes emanating from the qualitative aspect of this study show that participants were positive about the adoption of arts activities for individuals living with CKD. The outcomes of a survey conducted among patients, who had been presented with the opportunity of engaging in arts and crafts activities while on dialysis, emphasised that there is increasingly an interest in activities such as these [32]. This study concluded that staff within dialysis units who do not offer art or craft during haemodialysis are "missing an opportunity to improve the experience of patients" [32]. Other authors have previously described a more structured "Arts in Medicine" programme for individuals on dialysis [33], although, as highlighted by a recent publication [34], the cost associated with an approach of this scale and ambition may be a barrier for many institutions.

In terms of positive outcomes for people living with CKD, those who had been involved in the provision of arts activities in renal units reported how the arts improved individuals' emotional and mental well-being and

enhanced positivity. These findings support a number of systematic reviews, reporting that arts-based interventions improve symptoms of anxiety and depression in older adults [35], in people receiving bone marrow transplants [36], and in people with cancer [37].

Theoretically, a recent, comprehensive review conducted on creativity and mental health [38] proposed a psychosocial model. This model identifies three key themes which are influenced by engaging in creative activities: namely, emotional regulation, cognitive flexibility, and social connectedness. In terms of emotional regulation, the review [38] describes how engaging in creative activities provides an outlet for emotional expression and regulation, which may subsequently enhance response flexibility when in stressful situations [39, 40]. Creative expression allows individuals to express their emotions, whether positive or negative, in a tangible way [39], hence providing a feeling of control over their internal experiences [38]. This is particularly applicable to the renal population, who often feel a loss of control over their own use of time, which is monopolised by haemodialysis sessions. Another way by which creativity impacts on emotional regulation is by allowing the individual to enter a state of flow [41], a psychological state which tends to be characterised by deep engagement, focus, and a sense of timelessness, particularly relevant to being on haemodialysis, where existential boredom impacts heavily on mental health [5]. Individuals receiving haemodialysis can experience existential boredom [42], and findings from the current study reinforce the view that arts activities can reduce levels of boredom equipping patients to make more constructive use of their time when engaged in creative pursuits while on haemodialysis.

Cognitive flexibility, the second theme within this psychosocial model, has been described as an individual's realisation that they have choices in any given situation and their confidence in the notion that they are able to adapt and be flexible as required [43]. Jean-Berluce's [38] review of the literature proposes that engagement in creativity provides the individual with a sense of agency and control over their own thoughts and action, which can subsequently affect their mental health in a positive way. Social connectedness, the third and final theme which makes up Jean-Berluce's [38] psychosocial model, is also relevant to the current study, which reported the development of positive relationships between staff and individuals living with CKD following the introduction of arts programmes into renal units.

In a recent review [44], arts engagement was found to reduce cognitive decline and increase well-being and quality of life in certain populations, such as the elderly or

those with severe disease. Individuals with CKD are at substantially higher risk of cognitive decline than the general population; therefore, engagement in arts activities is particularly important for this group.

Some of the positive experiences of arts activities identified in the current study reinforce findings from previous research [45, 46]. Tesch and Forbes [45] (p. 5) discuss artworks as providing a “legacy” for individuals with CKD after they have died or left the unit for transplantation, as well as the positive impact arts activities have had on the “atmosphere and environment” within the renal dialysis setting. A qualitative evaluation of an arts activity conducted in Ireland [46] exploring the perceptions of arts activities among both individuals with CKD and staff on a dialysis unit revealed positive results, mainly in terms of better mental health outcomes and lower levels of boredom for patients, but also improved communication between staff and people with CKD and an increased sense of community on the ward.

Limitations

While extensive efforts were made to broaden the scope of participants in the PAINT survey, respondents were limited to individuals whom authors and their collaborators were able to reach within their existing networks and those of the project partners. It is recognised that there are likely to be numerous arts programmes globally conducted with individuals living with CKD, which have not been captured within the current study.

As there is no calculation of sample size in this study, we cannot be sure that the sample size is representative of the population. As mentioned in the Methods section, it would not have been possible to accurately determine the number of renal units worldwide to base a sample size calculation on. It should be noted as a limitation that the survey responses from the Philippines ($n = 14$) were almost all from the same hospital. This was due to one of the project partners being based in this hospital and encouraging colleagues to participate.

In terms of those who refused to participate in the survey, 114 people clicked on the Qualtrics link and opted out of completing the survey. It is difficult to deduce why this was the case and no details of those who refused to participate were captured.

The participants are likely to have been aware that the research was being conducted by members of RAG who have an interest in how the arts can have a positive impact on individuals living with CKD. Qualitative researchers

are aware that social desirability bias may therefore be possible in regard to participants’ responses, and acknowledge this is a common issue within the realm of qualitative research [47]. The research team attempted to minimise the potential for social desirability bias by assuring participants of anonymity, using open-ended questions, building trust and rapport with the participants during the course of the study, and encouraging participants to share their true experiences and perspectives [48].

Conclusion

The current study confirms and reinforces implementation of arts interventions globally for individuals in renal units: those kidney practitioners who have adopted arts activities for people living with CKD have observed the benefits in action. Further person-centred research attention and funding should be focused on the provision of arts activities within renal units, as well as other hospital departments, to fully recognise the true potential of this innovative approach. The findings of this study will inform the ongoing development of recommendations for future delivery of arts programmes for those living with CKD. There is a lack of randomised controlled trials of arts activities in healthcare settings, and further qualitative exploration into participant experience should be integrated within such trials.

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Statement of Ethics

Ethical approval was granted by Queen’s University Belfast Faculty Research Ethics Committee (REC Reference Number: MHLS 22_138) prior to the commencement of the PAINT study. Written informed consent was obtained from participants to participate in the study.

Conflict of Interest Statement

The authors have no conflicts of interest to declare.

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Author Contributions

Trisha Forbes: methodology, data collection, formal analysis, writing (original draft preparation, review, and editing), and project administration. Anna Wilson and Helen Noble: conceptualisation, methodology, formal analysis, supervision, writing

(original draft production, review, and editing), project administration, and funding acquisition. Clare McKeaveney and Claire Carswell: conceptualisation, methodology, writing (review and editing), and funding acquisition. Chris Bailey, Jenny Baxley Lee, Mayleen Laico, and Claire Meaney: conceptualisation and writing (review and editing). All authors have read and agreed to the published version of the manuscript.

Data Availability Statement

The data set for this study can be provided by contacting the authors of the paper.

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