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## The benefits of creative arts programs for people receiving renal dialysis

**Leigh Tesch, Anne-Marie Forbes**

School of Creative Arts and Media, University of Tasmania

The interrelationship of the arts with our health and wellbeing is achieving increasing prominence as an area of study. The arts are recognised for giving people the opportunity for self-expression and a collective voice, as well as a reducing pain, anxiety and stress in hospital environments, and supporting community engagement and social connectedness.<sup>1</sup> The arts tell our stories, and for people with chronic illness, these stories can present an opportunity for their experience to be recognised, validated and understood.

People with chronic kidney disease (CKD), have significantly impaired kidney function. This is usually treated by regular dialysis treatment; a process that replaces the function of the kidney, cleansing the blood by removing waste and excess fluid. This treatment can be done at home or by regular attendance for 3 to 5 hourly haemodialysis treatment sessions, usually 3 times a week. This is life-saving treatment, but limits people's lifestyle, diet and quality of life, and can cause fatigue.<sup>2</sup> CKD is associated with an increased likelihood of depression, anxiety and social isolation.<sup>3</sup>

Art and health programs have been initiated in renal care, usually within haemodialysis units where artists facilitate and support art activities with people while they undergo treatment. These programs use a variety of art mediums with trained artists working, usually individually, with those who choose to participate.

There are a limited number of studies that have investigated the effects of the arts when used in renal dialysis setting. This paper will summarise the main findings of these studies and offer some examples from a recent evaluation conducted by Tesch of the renal dialysis program in Waterford, Ireland. Some quotations elicited as part of that evaluation from patients, family members and staff are included in this paper.

### **Coping with dialysis**

Two of the papers investigating the use of the arts for renal dialysis patients investigated programs offering a range of arts activities including writing, music, craft, painting and drawing. Corrigan<sup>4</sup> reported that participation in an art program relieved boredom, improved mood, offered expressive opportunities, and built a sense of community. Participants in a similar Arts in Medicine programme studied by Ross EA, Hollen TL, Fitzgerald<sup>5</sup> noted improvement in quality of life indicators, particularly in the areas of social connection and pain perception, and a trend of improvement in scoring on depression scales.

### Engaged focus on art activity

These studies suggest that engagement with arts while undergoing dialysis provides a mechanism that can assist with the challenges of this procedure. The program run by the Waterford Healing Arts Trust in Ireland uses an artist-led and person-centred approach that was described as ‘enjoyable’, ‘relaxing’, and offering something to look forward to. A sense of accomplishment and control was also reported as participants, ‘that you can show to people that you’re able to do something...[that] you’re proud to show off’. The regular long periods of time that people are attached to the dialysis machine offer a unique opportunity to focus on an arts activity and become totally engaged, to pass the time, relieve boredom or become distracted from the process:

... you start drawing and you are in your own little world... you don’t think about what’s going on around you, you are in the middle of what you are doing. Next thing all of a sudden, dialysis is over.

### Skills

For some patients, it can be a time to develop new skills, develop mastery and build confidence. For others, the dialysis itself helped them feel well enough to re-engage with arts they previously enjoyed. For example, one staff member at Waterford said of a patient: ‘when she went to dialysis she got back into her art again. She felt well. So, she started to paint ...’ Her son said, ‘The time she was on dialysis, I got my mum back again.’

### Adverse reactions

In the literature reviewed, some studies considered specific arts interventions that may ease the dialysis process. A few clinical trials investigated the effects of music. Listening to music can improve the experience of dialysis by reducing the impact of adverse reactions, perceived physiological and psycho-social stressors.<sup>6,7</sup> Adverse reactions such as pain, nausea, and cramps were measured by Koca Kutlu<sup>8</sup> pre and post listening to music, and a significant reduction in the perception of pain and nausea was found in the experimental group when compared to a control group. Some studies considered biomarkers, and reported oxygen saturation improved after listening to music.<sup>7,9</sup> Self-reported levels of pain, itching, and improved mood of patients were shown to improve after live saxophone music played to patients on dialysis for 30 min for a 4-week trial.<sup>9</sup>

### Mood

Studies have also showed there was a reduction in anxiety scale measures after listening to recorded music in the experimental group when compared with the control.<sup>6,10,11</sup> Trends of a reduction in symptoms of depression were also noted.<sup>10,12</sup>

The music interventions in these studies were listening to play lists or live music, representing passive arts engagement. This can be helpful in dialysis settings when there are physical restrictions resulting from cannulation or blood pressure monitoring that can restrict the use of both hands.

### Reflection and understanding

Amidst the challenges of illness and dialysis, the arts can provide a sense of purpose and meaning. As well as assisting to manage dialysis, the arts offers a process and a creative space to make sense of the experience. This can be reflective and transformative, while providing an outlet for personal expression.

Drawing has been used to understand the experience of dialysis for children<sup>13</sup> and adults.<sup>14</sup> Corrigan<sup>4</sup> found that arts participation supported self-expression, and other articles provide descriptive reports of personal experiences with artmaking,<sup>15</sup> and perspectives from staff.<sup>16</sup>

In the example of the Waterford program, patients described increased confidence, and an opportunity to contemplate, reconcile life issues and express their emotions. The chore and heaviness of dialysis treatment changed to a more expansive sense of oneself as an art maker. This transformative experience served to develop a new positive identity beyond the limitations of illness. A family member reported: 'It gave her a story. The story wasn't about going down to dialysis anymore, the story was about going down to [see the artist] ...' It put the sickness in a context, it was smaller, it made it smaller. Instead of the limitations of illness, the arts program gave an opportunity for expansion and personal growth.

## Stories and storytelling

Stories shape our experience into a form that can be communicated to others. Our stories not only describe actions, events and place, but give meaning that is personal and embodied as well as social and cultural.<sup>17</sup> We use the arts to communicate our stories and experiences. Understanding narratives of health and illness can deepen our understanding of how the arts may benefit people on renal dialysis.

Serious illness presents a disruption,<sup>18</sup> to our story, our sense of ourselves and our identity. In narratives about illness, Frank<sup>19</sup> argues that the storyteller is not merely talking about the topic of the illness, but embodies this experience. Coming to terms with this disruption is about renegotiating our personal story and understanding it through telling it to others.<sup>19,20</sup> The reciprocity and testimony of sharing stories about the illness experience explores our new constructions and perceptions—to make sense of ourselves.

Frank<sup>19</sup> also describes the postmodern context of illness. He argues that it is increasingly complex, with technological and scientific advances, specialised language, and increased dependence on expertise. There is an increase in chronic disease and diseases in remission, so that people are seen as 'well' but not 'cured', and illness is often unseen. We have more access to information and knowledge about the body and yet the individuality of suffering is not always recognised. Story gives us the person's voice, the individual perspective so critical for personal agency and person-centred care in this medicalised setting.

There have been a small number of narrative studies into living with CKD, that describe the complexity of the experience, the dramatic impact on people's lives and their families.<sup>21,22</sup> People receiving haemodialysis often experience high levels of vulnerability, disfigurement, confronting decisions and consequences,<sup>23</sup> a reduced sense of control, an ongoing struggle to cope with everyday challenges<sup>24,25</sup> and a process of continual loss and grief.<sup>26</sup>

People's experience of CKD has been described as disempowering, with a dominant discourse of paternalism,<sup>27</sup> and dependence on health care experts and medical technology.<sup>28,29</sup> The necessity of treatment for preserving life is restrictive but paradoxically offers freedom, a duality of dependence and autonomy,<sup>30</sup> and an uncertain future with the loss of hopes and dreams, yet the hope of transplantation.<sup>31</sup> Bruce et al<sup>32</sup> describe these contradictions as a 'pervasive liminality' in their study of narratives of people living with a life-threatening illness; 'being alive but not living' and being visible yet invisible. Schick Makaroff, Shields and Molzahn<sup>33</sup> describe the experience of life-threatening disease as embodied and at times 'unsayable'—difficult to explain in verbal language.

In the Australian indigenous context, people described experiencing disempowerment and dependence on health professionals,<sup>29</sup> as well as a lack of understanding about cultural obligations, language and cultural appropriateness between staff and patients.<sup>22</sup> There was also a desire from community to educate younger community members to prevent them having a similar experience.

Storytelling has been used as a data collection tool in renal settings with Australian indigenous communities. The study by Rix et al.<sup>22</sup> in a New South Wales aboriginal community used the concept of 'yarning' as a methodology to investigate participants' views. This method of 'yarning' or having a 'chat' is described as 'informal and reciprocal exchange of information'<sup>22</sup> and is considered a culturally appropriate community based participatory approach to the indigenous community.

Listening to and telling stories of the experience of living with chronic disease has been used to support self-management programs. According to a scoping review by Gucciardi E, Jean-Pierre N<sup>34</sup> storytelling recognises the unique individual experience of chronic illness, and offers shared and personal reflection as a tool in peer support. Story has been used in aged care, palliative care,<sup>35</sup> in visual storytelling projects with young people with chronic disease,<sup>36</sup> and has been linked developing personal resilience as stories are told, affirmed and accepted by the listener.<sup>37</sup> Several story sharing web-based platforms enable people to share their illness experience.

## Community voice

Shared stories build communities and a sense of belonging. Haemodialysis can be an isolating experience because of the impact of the treatment regime on lifestyle. The common experience of arts participation can build connections with others.<sup>4,5</sup> Sharing arts projects facilitates relationships with families and the general community. A family member from the Waterford evaluation explained: 'it meant that she had something to discuss with us ... People would call in to see her ... it made it easier for them ... because they didn't have to be talking to her about her illness.'

Renal staff involved with the Waterford program recognised that current best practice appreciates the importance of listening to the patient voice. They describe 'powerful' examples where patients delivered presentations to staff, created artworks or books that gave voice to their experience, affirming that 'I'm not this dependent chronically ill patient. I'm living with chronic illness, but this is who I am'. The literature describes a discourse of health worker paternalism and patient passivity in interactions around renal care, with communication tending to be biomedically focused and one way from practitioner to patient.<sup>27</sup> Recognising their artistic endeavour may provide a more holistic understanding of the person beyond the patient.

Western desert communities in Australia provide examples of community-led arts-health initiatives, where the remote community empowers their own approach for disease management and prevention.<sup>38</sup> For example, this community developed strategies to tell their stories, including film animations, to support education about CKD for their community.

Current understandings in public health draw attention to the importance of social determinants,<sup>39</sup> as major contributors to our health and wellbeing outcomes. Hall<sup>40</sup> calls for more attention to addressing these 'upstream' factors in nephrology care, to consider unmet social needs to be as significant as lifestyle or biological factors. Here the arts may have a role in understanding and expressing stories of CKD and raising community awareness.

## Artistic outcomes

Arts and Health practice has often debated the value of process vs product when considering a person's engagement with the arts. Arts programs in renal units may use 'passive' engagement in the receptive arts (e.g. listening to music) or 'active' engagement in participatory arts (e.g. drawing or writing a poem). Although this process of engaging in the arts is valuable, the artistic outcomes (product) can also have a role in raising awareness and building community through celebrating achievement, enhancing the environment and contributing to research.

There are examples in reports and websites of artistic outcomes such as artworks, exhibitions, theatre, poetry, published books, compilations of poetry and visual images,<sup>41</sup> and films,<sup>42,43</sup> produced by people who experience CKD. In one example, Walsh & Ledgard<sup>44</sup> describe an artist-in-residence project that used poetry, monologues and paintings from children and young people on dialysis to create a fictional play that was publicly performed. Discussion of this project sought to deepen the way that this work links with concepts of illness and hospital treatment and uncomfortable material around children's illness and death.

### Opportunities for recognition, celebration and legacy

Art outcomes in the Waterford program such as published books, events, launches and exhibitions were described as affirming recognition for the patient/artist and were often celebrated with family and friends. Artworks provided a legacy of the person after they have died or have left the unit for transplantation. As a family member described, 'My mum isn't with us any more, for us to have the few paintings that she did, that's a huge benefit that we have received.'

### The atmosphere and environment: 'the quality and human side of a hospital'

Aesthetics of hospital environments have been reported to improve patient recovery and staff wellbeing in the literature generally,<sup>45,46,47</sup> though little specifically about renal dialysis setting. The Waterford program was reported to contribute to 'humanising' and 'normalising' the renal unit by changing the physical environment and atmosphere.

### Dissemination of findings through the arts

Using the arts to disseminate or translate research findings is also to be found in the literature related to CKD. Bruce and Schick Makaroff<sup>48</sup>, give an example of a narrative research project, where research participants with conditions of cancer, CKD and /or HIV were asked about, and shared a symbol to represent, their experience of living with a life-threatening disease. These objects and their relevant stories were then displayed in the exhibition in a gallery space.

Art-based methods shared knowledge in an accessible and culturally engaging way in the study of Rix et al.<sup>22</sup> conducted in an indigenous community. One of the aboriginal elders from this study's reference group responded to the thematic material in a painting to illustrate the findings to the community, and an image of this was featured in the journal publication.<sup>22</sup>

Lapum and Church<sup>49</sup> investigated the experience of heart surgery and recovery, collecting narratives that described confronting issues of identity and mortality, a reliance on medicalised technology and routine, and a perspective of being unseen and unheard. Their dissemination project used poetry and photographic images presented in a 3-dimensional labyrinthine installation titled *The 7024th Patient* to represent the experiential and subjective qualities of the research findings.

## Current research project

This review of the current literature and consideration of current practice indicates that in the midst of illness and limitation, the arts can defuse, deflect and reflect the patient experience. There is little research specifically considering the unique situation of the renal dialysis setting and how the arts can support telling the story of this lived experience. Leigh Tesch is currently undertaking a PhD research project at the University of Tasmania which will investigate the stories of people with CKD who attend the Nephrology South renal dialysis unit in Hobart, and considering how storytelling can contribute to personal and community understandings of chronic kidney disease. This project will:

- gather stories—to learn about the experience of people with CKD undergoing haemodialysis, from listening to their stories through interviews, arts-based methods and observations, over a period of up to 12 months
- share stories—people will have opportunities to tell stories through creative art forms (such as writing, drawing etc), and they can choose to contribute their individual stories or artworks toward a culminating story exhibition or installation for people with CKD, families, and the general public
- investigate stories—to learn how research participants respond to these shared stories, including health professionals' perspectives about the stories of people with kidney disease.

Considering the story of a person with CKD through arts programs and arts-based methods can offer a way to improve the wellbeing of people with kidney disease and to increase community understanding about this condition.

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## Presenter

**Leigh Tesch** is a current PhD candidate investigating the role of the creative arts in supporting people with chronic kidney disease. She has a background as an occupational therapist, dance therapist and performing artist. Leigh has facilitated, coordinated and supported numerous arts and health projects in hospitals, community centres and with young children and families. She is passionate about understanding and sharing our stories through creative experiences to support our community wellbeing.