

Adolescents narratives of embodied experience of living with chronic kidney disease.

Colleen O'Neill
PhD Candidate,
School of Nursing and Human Sciences
Dublin City University



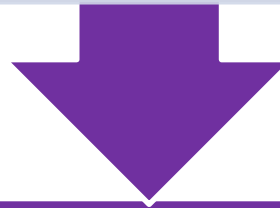
With sincere thanks to my
supervisors:
Dr. Briege Casey (DCU)
Dr. Veronica Lambert (DCU)



Aims and Objectives

Aim

The overall aim of this study is to explore adolescents' embodied experiences of living with chronic kidney disease



Objectives

Objectives: relate to the experiences and perceptions of adolescents with Chronic Kidney Disease in relation to:

1) the physical functioning and physical sensations of their bodies.

2) body image, self-perception and identity formation.

3) The body and medical treatment.

Chronic Kidney Disease

Overview of Chronic Kidney Disease

- Chronic Kidney Disease refers to the deterioration of renal function to such an extent that the kidneys are incapable of meeting the metabolic demands of the body.

Signs and Symptoms

- The kidney is a highly complex and sophisticated organ so failure to perform effectively results in profound physiologic effects such as impaired growth and development and malnutrition and anemia .

Treatments

- Renal Replacement therapies
- Studies have identified that adolescent perceptions of the effects of disease and treatment on their bodies can result in denial of disease, non-adherence to treatment and self-destructive behavior. (Wells et al 2012, Nicholas et al 2010,)

Embodiment and Chronic Kidney disease



- The literature reports that CKD can create vulnerabilities, which compromise the adolescent's ability to be autonomous and independent (Tjaden et al 2012, Nicholas et al. 2011).
- Several studies have identified that children with CKD experience a loss of control over their physical being and sense of body integrity (Tong et al 2013, Nicholas et al. 2011).
- Previous studies have identified embodied experiences as a critical area of research that warrants independent investigation (Waters 2008).

Methodology

Qualitative Approach

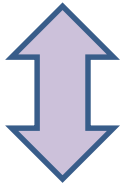
Narrative study using an ethnographic approach.

In the context of this study adolescents stories are accessed through ethnographic fieldwork; spending extended periods of time with the young people as they encounter and process body experiences.

Participants

- **Sample Recruited.**
- 5 adolescents living with CKD were recruited
- 1 male and 4 females aged between 10 and 17 years with a diagnose of chronic kidney disease.
- All participants were undergoing CKD treatment, including peritoneal dialysis, haemodialysis and/or transplantation.

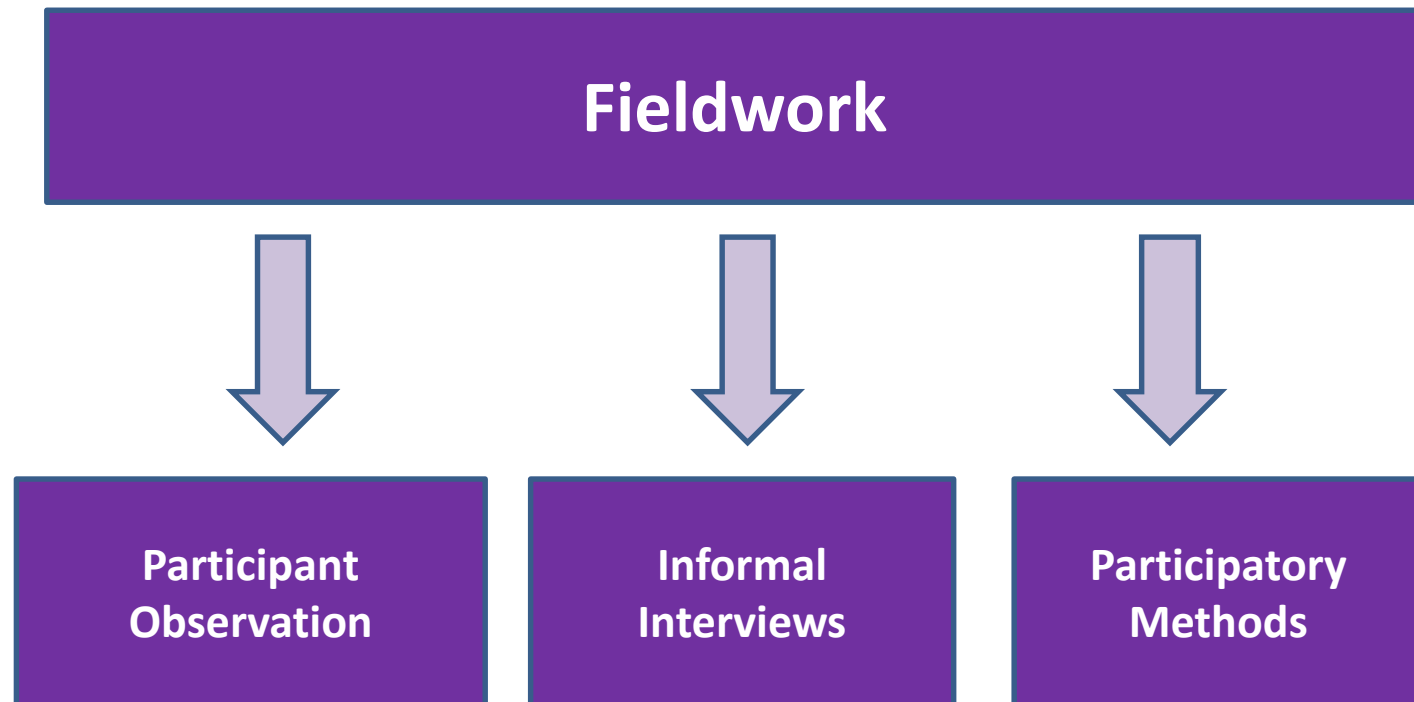
Setting



Fieldwork involves 4 key settings

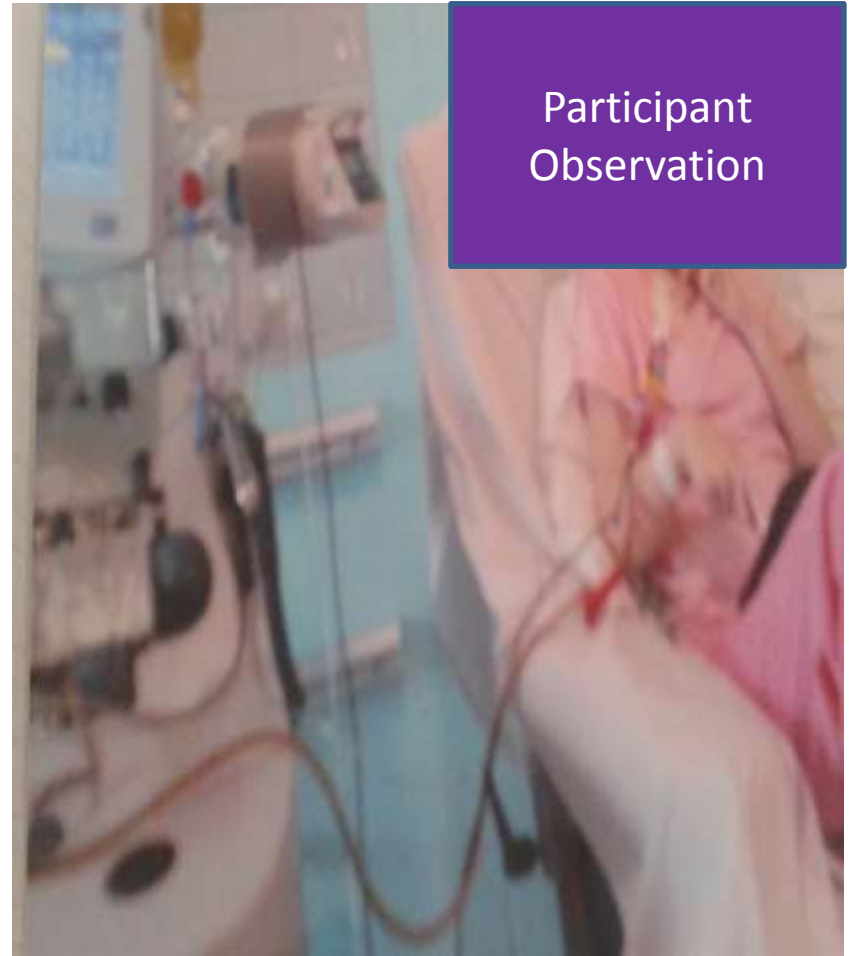


Fieldwork



Participant Observation

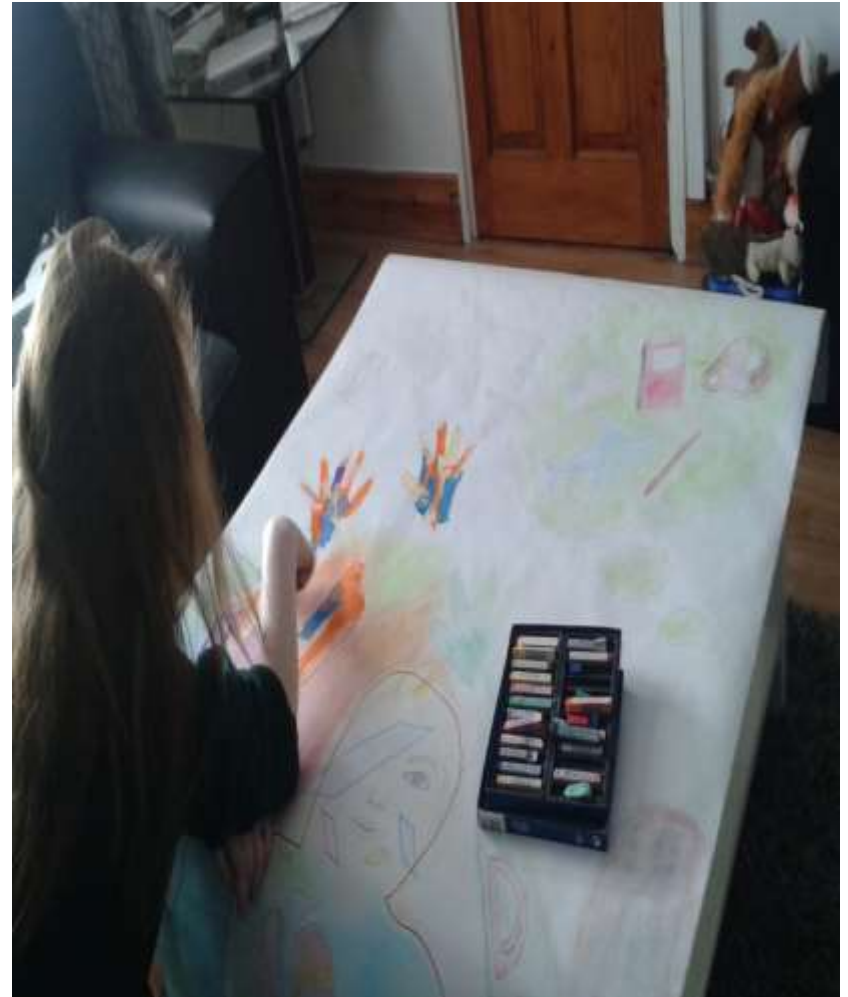
- Observation involved collecting data first hand in real life situations over a prolonged period of time i.e. 18 months in both home and hospital contexts to learn about adolescents daily experiences of living with Chronic Kidney Disease.



Participant Observation

Accessing Participants Stories

- Narratives collected during fieldwork or in some instances during a naturally occurring conversation between the researcher and the adolescent.
- Using informal conversations allowed for more interactive modes of interviewing, which reflect participant's ways of organizing meaning in their lives and provided insight into the subtleties and complexities of living with CKD.



Participatory Methods: Body mapping

- The body is like a gallery of one's life recording the body's journey through injuries, scars, birthmarks, illnesses and everyday life experience .
- Body maps assist people to access their bodies (ASRU 2004) – synergies with the study focus on embodied experience.



Participatory Methods: Body mapping

- Body mapping is a means of externalising somatic-emotional experiences of illness revealing how the biomedical intertwines with an intimately personal history (Brett-Maclean 2009)
- Body mapping are broken up into 18 body mapping exercises the amount of exercises is consistent with previous research using body mapping (Solomon 2002).



Data analysis

- Riesman's 2013 narrative framework used to analyse interview data, field notes and body 'performance' in the body maps.
- The following segment provides an example of how a narrative was analysed using Riesmans approach to analyzing scenes which involves
 - the positioning of characters,
 - the positioning of self,
 - the positioning of their audience.
 - the language used

(Riessman 2007).

Short Example of Narrative

- The following segment was chosen as it demonstrates one adolescents struggle with identity and control.
- 'Aisling' is a 13 year old girl suffering from kidney disease since birth.
- Aisling has fluctuated between peritoneal dialysis/ haemodialysis and has undergone 2 kidney transplantations.
- Aisling is currently recovering from her second kidney transplant.

Short Example of Narrative

- *'I named it Ciara, I named her Ciara. I named my kidney Ciara'.*
- *'She came from Qutar'*
- *'I liked Ciara Kidney. I know it came named with a K. She came K but I said I'll agree with Ciara but I want it to be a C'*



Short Example of Narrative

- *The only time she didn't go out at all was last week, last Thursday and we didn't go out at all at night she didn't she was just too tired.*
- *'Ciara didn't go out to the bathroom at all!. Since she has been taking me out at least 4 times (a night)' and I'm like Nooo!*
- *I am very sorry Ciara is calling. LIKE SERIOUSLY she doesn't even do it calmly she just feels like I'm bursting to go.*



Short Example of Narrative

- The work that the narrative does involves identity work.
- The narrative demonstrates Aishling's attempt to understand the changes in self and her relationship to the new organ in her body.
- Aisling sees Ciara the Kidney as separate from her body and positions Ciara Kidney as a separate person referring to her new kidney as 'she'.

Short Example of Narrative

- Aisling trying to come to terms with the disruptive transformation of a new and functioning body.
- Aisling appears overwhelmed by the physical sensation of having to urinate, a sensation which up until this point in her life never had.
- This has implications for her physical body, which is expressed in the level of tiredness she experiences as a result of having to urinate, a problem which she blames Ciara for.
- The narrative demonstrates how Aisling is processing and adapting to a new and functioning kidney and body

Visual Analysis: Body Mapping

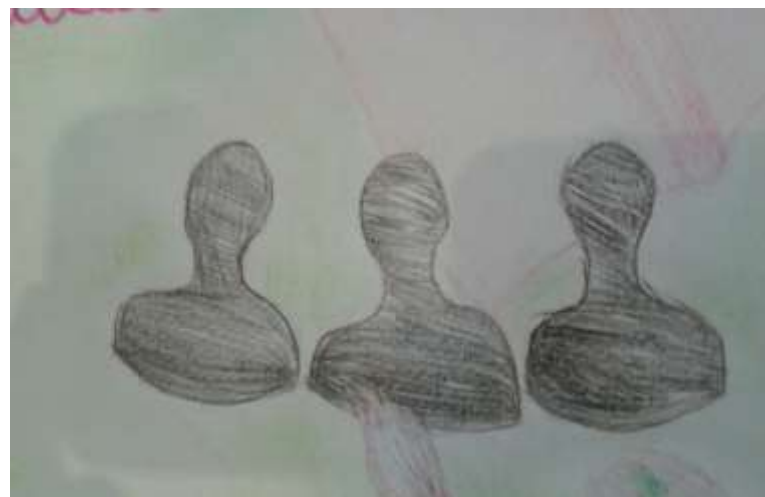
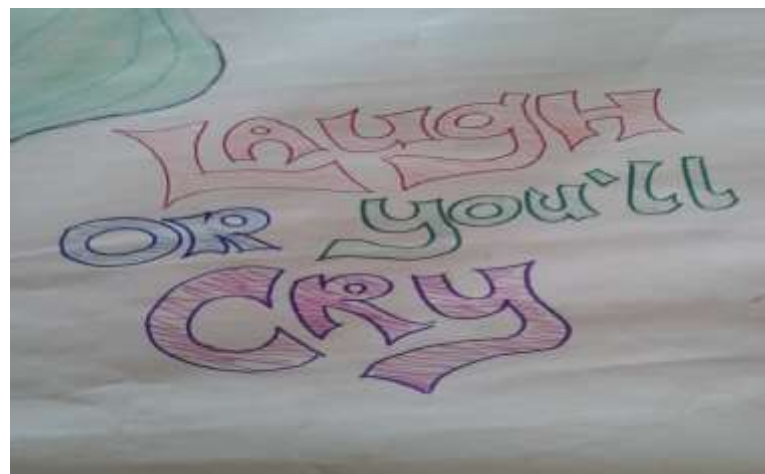
- Body Maps: the perceptions and interpretations of the young people were actively sought regarding the meanings and intentions of their body map







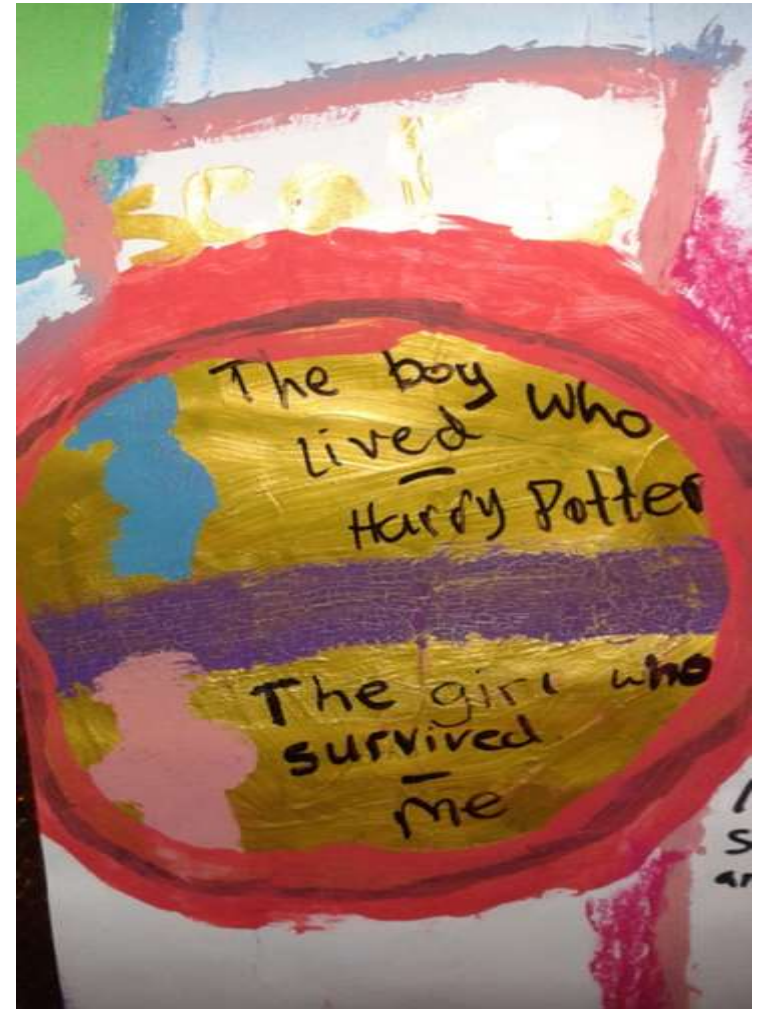
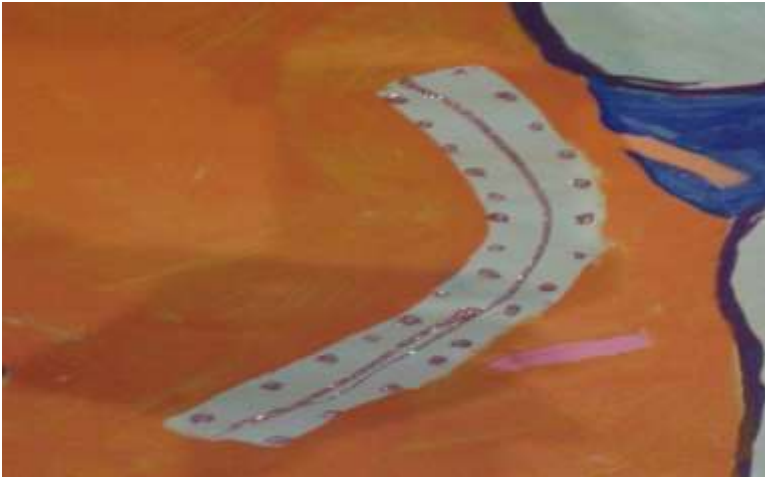
Stories from the Body



Stories from the Body



Stories from the Body



Stories from the Body



Stories from the Body



- Adolescents described the consequences of CKD and treatments, which left them feeling tired and sick all the time.
- *I'd always be tired'*
- *'You could sleep for 12 hours and then wake up and be more tired'*

Challenges

How do I organise and deal with the wealth of data collected?

How do I analysis visual data using a narrative approach?

How do I determine which stories to tell?

- Any questions?

