I’M HERE BUT I’M NOT
A Photovoice Exhibition of Living with Rheumatoid Arthritis
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FOREWORD

We are delighted to present to you a collection of photographic work showcasing people’s everyday experiences of living with and managing chronic illness. “I’m Here but I’m Not” showcases the lived experiences of people with rheumatoid arthritis, an inflammatory auto-immune disease, often characterised by severe pain and fatigue.

Rheumatoid arthritis, and similar chronic illnesses, are often described as “invisible illness”. We hope that the images featured here are a first step towards raising awareness around living with a chronic illness by making rheumatoid arthritis more visible. We hope to spark debate and discussion about how we can make positive changes to better support people to manage the condition in their everyday lives.

Exhibition Committee
Dublin, Sept. 2019
This is a participatory project conducted by social researcher, Dr Susie Donnelly and visual artist, Claire Dix. It is part of a larger academic study to understand the patient’s perspective of challenges and solutions to self-managing of RA and identifying solutions to support them.

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INTRODUCTION

Rheumatoid arthritis (RA) is a highly prevalent chronic disease affecting about 1% of the global population and approximately 40,000 people in Ireland. It is characterised by inflammation of the joints and tendons causing pain, stiffness and swelling. Without proper treatment, it is associated with increased mortality and reduced life expectancy.

Self-management is an integral part of successfully treating RA. It refers to the daily tasks that individuals do to keep their illness under control; minimize its impact on their physical health and functioning; and cope with the psychological consequences. This includes having the confidence to deal with medical management, emotional management and behavioural management of their conditions.

However, not everyone with a chronic illness encounters the same problems when ill, ‘...for the simple reason that their social and bodily circumstances are not identical’ (Radley 1989: 233). We should recognise that not everyone will or can manage their illness in the same way, and that supports for self-management need to work for a diverse group of people.

It is increasingly important that we deepen our understanding of the patient experience of self-managing chronic illnesses, such as RA. Chronic illness is a growing burden for healthcare systems worldwide.

This photo exhibition is an important part of a wider study being carried out by researchers in UCD Centre for Arthritis Research (CAR) and UCD Centre for Interdisciplinary Research Education and Innovation in Health Systems (IRIS) to explore solutions to improve the self-management of rheumatoid arthritis. The exhibition aims to raise awareness of the lived experience of chronic illness and create a dialogue around the challenges and solutions to living with the condition.
The aim of this project was to explore the experiences of people managing rheumatoid arthritis, using a method of participatory photography known as photovoice. Photovoice is a research methodology and an advocacy tool which uses photographs, coupled with facilitated group dialogue and photo-captioning, to give voice to people’s lived experience of a particular issue.

**PROJECT DESIGN**

**METHODOLOGY**

Twelve people participated in this project; nine women and three men. Participants were recruited via social media, local newspapers and the Rheumatology clinic at the Mater Hospital, Dublin.

Participants took part in a series of group workshops and a one-to-one interview with the researcher.

In the first workshop, the group was introduced to the aims and objectives of the project and to the photovoice methodology. Each member of the group was given a digital camera and instruction on how to use it – no prior photographic experience was required for participation.

Within a few weeks of the workshop, the researcher met with the participant in their home or a place of convenience to conduct an in-depth interview. During the interview, the participant selected photographs that they had taken to explore their thoughts, feelings and experiences.

At the final workshop, the group met to discuss and review their photos for exhibition. They wrote captions to accompany them and shared a selection of their photos with the group. All photographs and captions were displayed on the walls and participants were asked to vote for the photos they would like to put forward for the exhibition; they could vote for their own photo or that of someone else. A final shortlist of photos and captions was reviewed and the group began to identify themes that captured the output of their group. Finally, the group discussed details of organising the exhibition (e.g. Where? When? Who to invite?).

A representative from each group volunteered to form an exhibition committee to work more closely with the researcher and visual artist to organise and curate the exhibition.

In collaboration with the researcher and/or visual artist, each participant reviewed, and if desired, edited the final selection of photographs and accompanying caption they wished to include for exhibition.
ETHICS

Ethics Committees at University College Dublin and the Mater Misericordiae University Hospital, Dublin approved this study (UCD HREC LS-18-66-Donnelly; MMUH Institutional Review Board Reference: 1/378/2017.

Participants own the right to any data (e.g. photos or similar material) that they created during the study. Written consent to display these photos in the exhibition was provided by each participant and they also indicated whether they wish to be identified at the photographer or not. Photographs that feature any identifiable person(s) were submitted to the researcher with written consent from the person featured in the photo.
ACKNOWLEDGEMENTS

Thanks to our academic collaborators, Prof. Gerry Wilson, UCD Centre for Arthritis Research; Prof. Thilo Kroll and Dr Hasheem Mannen, UCD Interdisciplinary Research Education and Innovation in Health Systems (IRIS). Thanks to Dr Emma Dorris and the Patient Voice in Arthritis Research initiative, UCD.

We wish to thank the people and organisations who helped to spread the word about this study, including Arthritis Ireland and their many branches across Ireland. We would also like to thank the the Rheumatology clinic at the Mater Hospital for their support, especially Patricia Kavanagh, Laura Helbert, Kelly Leamy and Ng Chun Ruh. This work would not be possible without the funding provided by the UCD Wellcome Trust Institutional Strategic Support Fund.

This project has greatly benefited from the involvement of a Research Advisory Group, composed of people living with rheumatoid arthritis, who informed the early stages of the study and its design. They generously gave their time and effort to ensure the study was conducted in a way that considers the needs of people with RA.

A special note of thanks to the Exhibition Committee who were fundamental in organising and bringing together the exhibition.

Finally and most importantly, we would like to thank the men and women who participated in this project and generously gave their time and effort to create this exhibition. It was a pleasure to see how open and willing people were to share their experiences and to support one another, especially during the group workshops. Their wealth of knowledge and experience will hopefully now serve as a resource to others with chronic illness, and all of those who live with it; from health care providers to family members.
Rheumatoid arthritis (RA) reduces functioning in the joints and can involve persistent pain and fatigue. People with chronic illness often have to adjust what they do on a daily basis and learn how to adapt to the illness. They may need to think about how, or even if, they can take part in everyday tasks and social activities. This can be difficult for family, friends, colleagues and wider society to truly understand.

Participants in this project came up with the theme - I’m Here But I’m Not – to reflect photographs they had taken which represent the experience of living life in the background, and feelings of a life unfulfilled. The following photographs represent this idea.
I'm here but I'm not

© JACINTA

I can't see. I can't hear.

I am wrapped up in myself trying to take one step in front of another so I won't trip. How am I going to answer the woman in the shops questions?

I don't know the answer. I can't think straight. I look and sound like I'm drunk and I can't even express what is really going on. I'm too tired.
With RA every morning when you wake up, the first thing I find I do is see what number I’m at on the pain scale and then is it a “hard” 8 or an easy “8”- always influenced by whether or not you’ve managed to get a full night’s sleep on the pain front. On this particular day it was hard 8, one of those days where you really don’t want to do anything other than simply cope with the pain and the unrelenting unremitting nature of it as best you can. BUT you’re a person who is more than just their disease, you’re a wife and mother. You have obligations. You get up, get dressed and head to the sea side for the fun day out you promised your kids.

On a day that’s a hard 8 though, your hands, fingers, wrists, are all too sore to be able to manage holding hands with your children. Imagine, holding hands with your 3 year old hurts too much? It’s a hard 8 all right. So I sat with my baby in her buggy and watched my children have such fun with their dad as they ran, jumped, splashed, got soaked and enjoyed their lives but wondered why I wouldn’t or couldn’t join in.

The photo shows a sea of two halves for me. A beautiful calm sea far out, sun shining, and anyone walking past would have seen a dad having a great time with his children. For me I see the bit where the waves are crashing and breaking against the shore- the force of the waves represent my anger and rage at the disease, the havoc it has brought into my life. The crashing and breaking of the waves is often how I feel the disease attacks my body- it’s full on and pulls no punches.

At times RA pulls you under like it’s a rip tide and before you know it you’re lost at sea.
I’m here but I’m not

I used to love travelling.

I still do but it’s now painful and tiresome. The trip itself can be exhausting but even going on the airplane hurts. Cramped seats and uncomfortable positions create pain and swollen ankles.

Window

I see it but I can’t get myself up and washed to go.

© JACINTA

© AMANDA
Fatigue hits at all times.

Napping during the day is often a must.

It’s indiscriminate and happens without warning.

No fishing anymore

In the distance is a small fishing boat which reminds me that I can no longer participate actively in fishing due to my arthritis in my finger joints.
I’m here but I’m not

© AMANDA

My sister walking ahead of me.

Surgery and stiff ankle joints slow down my walking speed. Everyone passes me on the street. I’m always lagging behind and it takes twice as long and twice as much energy to walk anywhere.
Steps of acceptance

A loss of self and a loss of identity describes what I see when I look at these shoes.

The first photo shows four pairs of shoes marked with Post-It's and the words: Pre-RA Work, Pre-RA Wedding, Pre-RA Night Out, Pre-RA Funeral.

The second photo shows four pairs of shoes with Post-It's and the words: Post-RA Work, Post-RA Wedding, Pre-RA Night Out, Pre-RA Funeral.

I’m here but I’m not
There is no cure for rheumatoid arthritis. But clinical studies indicate that remission is more likely when treatment begins early with medications known as disease-modifying antirheumatic drugs. These medicines can be taken by mouth, be self-injected or given as an infusion in a doctor’s office. A physical or occupational therapist can teach you exercises to help keep your joints flexible. Surgery may be considered to repair damaged joints.

The participants talked about the many varied ways they “treat” their RA, from using aids and devices to finding ways to outsmart the condition. They reflected on how they feel about these solutions, and what works for them both physically and mentally.
When I was 35, I found out I had rheumatoid arthritis because it had destroyed my knee. I faced a new chronic illness and a total knee replacement in a span of 3 weeks. This was the walker I used in recovery from my surgery. Even though the walker was temporary, my body still feels like it aged well beyond my years.

In an acute illness like a throat infection you take your antibiotic, you get better and that’s it. Whereas chronic illness is medication for life and Rheumatoid Arthritis is certainly medication for life.
**Hand me down, pick me up**

My grandfather’s cane, lent to me by my aunt during some difficult days.

**Window to my world**

Coffee, biscuits and Facebook. Getting my meds sorted for the week.
Ah! Pain Relief.

This is my granddaughter (aged 8), squeezing my finger as she realizes that by doing this, that it causes relief from pain for me. She does this voluntarily from time-to-time, especially when she sees me winch.

Wash It All Away

People offer advice all the time. You frequently get asked “have you tried…..??”

One piece of advice that I am happy to go along with is to enjoy the healing benefits of the sea.
Man’s Best Friend

With RA came a subtle separation from others who I would have played sports with on the weekends. As I couldn’t participate I simply didn’t see them as much. I was figuring out through trial and error, which physical activities were possible to maintain and which were not. During this time having a fluffy loyal buddy was a real benefit. Some days rest is necessary and she’s happy with that, but here she is pictured at the coast - on a good day.
Meds-
my best friend when I have a bad day.

I am walking.
So good to walk after so many years of not being able to. I was asked to look after a dog. That morning I put my foot on the floor and could not stand. My whole left side hurt – Don’t make any plans!

I cannot see the lovely scenery around me. All I feel is pain. The sun shines and everyone is dressed up, but not me. I'm not smiling and I'm dressed badly. I try to be grateful for what I can do, not what I look like. I see some young girls – not that young – sitting at a wine bar laughing at how I’m dressed, but I just have to keep going.
I started messing with art after I got RA. I call it messing because it was all pretty bad. But I finally bought a moleskin notebook and started. Thank goodness for this. I am not so engrossed in my pain when I mess. I don’t do it a lot but when I do, I love it. My eyes light up talking about it. I can journal on the page and just cover the page with gesso. Perfect.
I won't shop anywhere that doesn't have one.

Pain free gear change

Medicine in all its forms
Nearly a million people in Ireland are affected by arthritis. That’s more than one adult in five. It is the country’s biggest single cause of disability.

Early rheumatoid arthritis tends to affect your smaller joints first, particularly in your hands and feet. Symptoms often spread to the wrists, knees, ankles, elbows, hips and shoulders. The disease produces a painful swelling that can eventually result in bone erosion and joint deformity. The signs and symptoms of RA may appear and reappear, known as “flares”.

Participants spoke about the need to see some kind of proof of their illness. Swelling and inflammation of the joints provided evidence of RA in their bodies. The photos featured in the theme, Visible Illness, make the presence of the condition real, either for the participants themselves, or for others.
Not Today!

My rings not fitting almost became a representation of the beginning of my RA. They did not fit me for about 12-18 months after the onset of my RA symptoms. On the day of baby’s christening I was upset that I was not wearing any rings so I bought a cheap ring, I love that ring so much now because I got comfort on that day that I was wearing a nice ring! My friend has a jewellery shop and she offered to change the size of my rings but I said no because that just meant to me I was accepting my swollen hands and rings were forever! … About a year after starting medication my fingers were ok and my rings fitted me again. But I have days now, they don’t fit me and it just brings me back to the low period in my life where I was worried constantly about my fingers and hands.

So this picture was taken on a bad day recently when I felt fatigued and my hands were swollen and my rings did not fit. It was like my hands were saying ‘no rings today’! I just felt dreadful, I was really tired my finger was really swollen I couldn’t put on my rings. And there’s the picture …just like, not today! …
Visible Illness

Untitled
Visible Illness

How the Penny Dropped

Morning weakness, achiness and stiffness in my hands meant not being able to open my fingers wide enough to hold the bannister on my way down stairs, it also meant struggling to properly grasp and lift the kettle as I made my morning coffee. These first symptoms were what lead to a RA diagnosis being suspected.
Visible Illness

Untitled
They increase and multiply....

with knobs on...

Visible Illness
MIND YOURSELF

In Ireland, you will often hear people using the phrase, “mind yourself” as they bid farewell. When you have a chronic illness, self-care, being kind to yourself, and being in touch with how you are today, becomes a vitally important aspect of your daily life. Mind Yourself was a theme that represented this for the participants.

In order to mind themselves, they were conscious of doing things that made them feel normal; to feel good; doing things that allowed them to connect with their environment and their community. They spoke about finding peace and the healing power of nature. These things provided them with a sense of optimism to overcome the challenges they face by living with RA.
Minding Mind and Body, One Splash at a Time.

Early morning swims with my local swimmers group helps me feel strong physically and mentally. Out at sea, whilst moving through the waves, listening to the seagulls and watching out for jellyfish; I’m taken away from terrestrial problems of aches and pains, and wonderfully I get to carry an element of this buoyancy through the day.
If you would like further details regarding this project, please contact

Dr. Susie Donnelly
susie.donnelly@ucd.ie
or +353 01 716 6462