Analysis

I need duvet days

Shattered. Broken.

Numb. Empty.

Physically, and emotionally.

It's very invisible.

I am sick all the time.

I'm fed up with it, and I'm trying to live my life without it.

But it's getting worse.

My brain is working but my body can't do it.

It started in one bit of my body and now other bits of my body follow.

I can be as well as possible and with a full life.

But I think of myself as a perpetual patient, as disabled.

It isn't how I thought my life was going to be.

January 2018

Nicole Brown

Data

Overall, the data took one form of three: pictorial submissions through photos, the accompanying email explaining the photos and the interview following the identity box project. As the identity box project was the same for all participants, the following graph is supplied to identify the materials submitted:

	Who are you?	What affects you?	How do others see you?	What role does fibromyalgia play?	What is life with fibromyalgia like?
Dorothy	pony tail, Hessian libra wall hanging, needle and thread in red	photo of twin sister and brother, two letters, carboard cut outs, medication, jigsaw piece	nail, light bulb, diary/calendar	swimming goggles and timetable, country club membership card, apple, a torn piece of orange paper	sent an email letter explaining thoughts
Charlene	smiley face, turtle, angel, diamond	my children	rock, also sent an email letter explaining thoughts	sent an email letter explaining thoughts	sent an email letter explaining thoughts
Charlotte	marriage certificate, one gardening glove, broken cooking measure	photo of husband, thermometer, figurine representing friends, cookery book	snowman figurine, cookery book, paintbrush, needle and thread	broken watch, a broken piece of tree, a bent nail, an empty, hollow toilet paper roll	a series of photos created specifically for this project to depict "shattered", "frustration" and "empty"
Lisa	a paint brush, spool of thread, bottle of glue, photo card of family journal, also sent an email letter explaining thoughts	book of prayers and beads, book, music box, flower, adrenal insufficiency magnet and hydrocortisone	doll with the face drawn upon it	native Texan sticker, calendar, mobile phone, mobile phone clock, volunteer ID badge, playing cards, book, soft fabric in green and blue, box of decaffeinated green tea, also sent an email letter explaining thoughts	sent an email letter explaining thoughts
Sally	a plain box, a candle, a glittery heel, passport	sunglasses, makeup, condom, staff badge	pen, pawn, safety pins, box of hay fever medication	a mind map explaining thoughts	a pillow on top of the box

Results

The analysis of the identity boxes with the related emails and the interviews revealed several common themes in relation to factors influencing the construction of identity under the influence of fibromyalgia, the relevance of support networks, the connections between the experiences of fibromyalgia and work/life balance. The following section will be focussing on losses and gains due to fibromyalgia and the battle with fibromyalgia.

Losses

The onset of illness often coincides with the experience of loss and not being able to do or have what was once planned. All participants covered the experience of loss in the interviews, email communications and the identity box, although the women did not always refer directly to the feeling of loss. In response to "What role does fibromyalgia play?" Lisa added a volunteer identification badge and a deck of cards to her box. Both items represent activities that she is no longer able to pursue in her life:

> Volunteer ID badge for local hospital - I have had to resign as a volunteer from several organizations. Not enough energy. Not knowing if it will be a good day or not. Which days would be good - no one knows. No more volunteering.
> Playing cards - I used to play cards every Monday. Now that is not always possible. I miss my card playing friends. We hope to get together soon. (Lisa, email)

In a similar vein Dorothy also recalls activities and relationships that she has lost due to her life with fibromyalgia:

> For over 20yrs I used to socialise with my partner at our local Country Club, but now I use my Chemist Rewards card more than my Country Club Card (photo B). I can't work anymore & so I receive the Disability Pension. There's a card for that too, the blue one in photo B (Dorothy, email).

While Dorothy appears to demonstrate hints of sarcastic humour in her communication, Lisa is very factual, curt and abrupt in her email. The conversation with her demonstrated that Lisa felt disappointment, sadness and frustration, but that she did not allow herself to indulge in or be overcome by this feeling of loss:

> I have tried to removed [sic] stress from my life and accept the cards that have been dealt. As long as I stay proactive and not give in to any of my medical issues, life is good. Self-pity is not in my box of choices. Life is too precious to waste it. If I need prescription medication to help me through the day, so be it. If I need a nap, so be it. If I need a hug, I ask for it. If I need a friend's ear, I ask for it. (Lisa, interview)

Charlotte expressed her experience of loss more openly and directly. She used a broken watch and a broken twig to represent the role of fibromyalgia in her life. The brokenness in itself was a powerful statement, but this was reinforced in two items. Charlotte already alluded to the theme of being broken in response to the first question "who are you?" where she says "I am also a bit old, a bit used and a bit broken" (Charlotte, email). But the depth of her brokenness and therefore the loss she was experiencing became fully evident in her description of the watch and the twig:

> I have a broken watch, which depicts the time that has been stolen from me; the inability to move forward in my life. I have a broken piece of tree that represents my family which shows some parts have been broken and some have actually been severed because of my pain medication (Charlotte, email).

In the conversation with her, Charlotte's experience of loss became more nuanced. Talking about no longer being able to practise her chosen profession as a paramedic, to play her 12-stringed guitar or to make her own artisan breads, she no longer appears to be a broken person, much rather a person who mourns the pre-fibromyalgia self:

> it's sadness because I can no longer do these things. And I'd love to be able to do them again. I guess it's more of a melancholy feeling, kind of like "I miss it" (Charlotte, interview).

However, when probed about the broken and severed ties with her family, she spoke of resignation. In order to help her manage her fibromyalgia symptoms Charlotte had been prescribed marijuana, which some family members did not agree with. In Charlotte's view, she was only taking medication to help her cope, whilst some family members "have gone so far as to try and stage an intervention". In this context, she clearly did speak of loss, but not her own, more that of her family's:

> they have chosen to distance themselves from us and that is their loss. I cannot chase a relationship that isn't meant to be (Charlotte, interview).

Sally, the youngest and the only participant in employed work, voiced her experience with fibromyalgia more strongly:

> To me fibro robbed me of my dreams. I wanted to be a criminal psychologist but I struggled do [sic; so] bad at uni I couldn't carry on with it. My partner left me because he couldn't handle how little I did. Friends have left me because I don't go out much anymore. I see it [fibromyalgia] in a bad way, but when I have control of it it's not that bad, it's just difficult to stay in control and hard to get back once I've lost it. Both my pain and my tiredness has [sic] an impact on me. It stops me being who I want to be (Sally, email).