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**A cross-level, intersectional feminist perspective of patient empowerment
through mobile health applications: a case study on the app 'RheumaBuddy'
for rheumatoid arthritis.**

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Abstract

The importance of patient empowerment has emerged as a key dimension of contemporary healthcare policy and delivery under the paradigm of the democratisation of healthcare. This thesis focuses on digital health (DH) interventions, particularly mobile health applications, and their role in patient empowerment. The aim of this research was to highlight the importance of a multi-level analysis of empowerment through DH, which takes place on micro (intrapersonal), meso (interpersonal) and macro (structural) levels. Qualitative research through interviewing was conducted alongside Daman, a digital healthcare partner, in relation to their app 'RheumaBuddy' for rheumatoid arthritis (RA).

This study utilises a multi-level analysis of empowerment under intersectional feminist theory, illuminated through a case study on the mobile health app 'RheumaBuddy'. A multi-level analysis is imperative when considering empowerment due to issues associated with a single level analysis which often forgoes the nuances associated with the true lived patient experience. This affectively ties in with an intersectional feminist perspective, which argues that power and identity intertwine to impact the oppression of marginalized individuals. Aspects related to power and identity as associated with intersectional feminism heavily influence patient outcomes on micro, meso and macro levels.

The results of this study align with the hypothesis that a patient experience of (dis)empowerment is conducive to their position in the social world and interwoven between the three ecological levels. Therefore, we should consider all three levels and a patient's social position when considering patient empowerment through DH, as opposed to heavily relying on the micro-level which privileges neoliberalist ideals.

This study shows how mobile health applications can be dualistically empowering and disempowering, affecting participants situated on different intersections of the social world in a distinct way. Going forward, DH interventions must be designed with an intersectional framework in mind.

The utilization of DH which is grounded in cross-level analyses and intersectional feminism can help alleviate health inequalities and bolster inclusion – but if not addressed, the health disparities we already see in our social world will only be amplified further through DH.

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Introduction

As an interdisciplinary scientific discipline, DH involves the use of information and communication technologies to address the health problems and challenges faced by patients and society. DH has been offered as one of the key solutions to aid in the improvement of chronic disease management. To develop a more nuanced understanding of how DH emerges in practice (Henwood & Marent, 2019), we arguably need to look beyond the medical and technological 'utopian' discourse (Lupton, 2014; Morley & Floridi, 2019) that prefaces DH, and be cognizant of the 'bigger picture' that the social sciences embody. DH for chronic illness is allowing patients to engage in self-care and remote monitoring with the aim of 'empowerment', which encompasses a multitude of factors such as any increased knowledge, autonomy, self-determination, authority or feeling of control over their illness (Pulvirenti et al., 2011). The issue lies in the fact that DH seems to be dualistically empowering and disempowering patients, while there are others who are simply indifferent (Lupton, 2013).

Pirhonen et al. (2020) developed the term 'Janus-faced conceptions of technology' to highlight the ability of technology, and in particular self-tracking technology for health, to benefit some while posing extra challenges for others due to a range of different variables. This paper argues that the level of (dis)empowerment experienced depends on a patients' social position on an axis of privilege and oppression – influenced by a range of socioeconomic variables. Therefore, it is imperative to be critical of DH interventions through an intersectional feminist lens. Considering 'empowerment' from its origin in a context of collective action and activism, the intersection of identity and power is at its pivotal focus – ultimately raising the question of: 'power, and for who?' (Drury et al., 2015). This is what is at the centre of intersectional feminist methodology. Although the intersectional feminist perspective emerged through critical racial and gender studies, this study researches the following variables which influence an individuals' social position: gender; age; geographical location; self-reported income; clinical status; years since diagnosis; education level; and employment status.

The cross-level framework as put forward by Logie et al. (2021) argues that patient (dis)empowerment is influenced by interpersonal (micro), intrapersonal (meso) and structural (macro) factors. Empowerment is a process, as opposed to an outcome – and utilising a cross-level framework highlights how a patient's healthcare experience is affected by these intertwining levels and the power structures within them. This paper puts forward the hypothesis that to more clearly understand how (dis)empowerment through DH emerges in practise, we need to analyse it with a cross-level, intersectional framework in mind. This follows the example from Winker & Degele

(2011), who advocate for an intersectional multi-level analysis when addressing social inequality, which considers reciprocal effects between the various levels.

This study focuses on one area the digital is being utilised in healthcare: the digitalisation of self-care in chronic illness management through mobile health apps. This experience will be illuminated through a case-study on the app 'RheumaBuddy' for rheumatoid arthritis (RA), which is currently in a redevelopment phase in anticipation of their clinical trial at the end of 2022.

The research question for this paper is as follows: How can patient (dis)empowerment through DH interventions be explained using a cross-level and intersectional feminist analysis?

The purpose of this research is to offer insights to DH creators from an intersectional social policy and public health perspective on how to ensure interventions do not reinforce the marginalisation already experienced by certain groups; and further disempower those who are already more likely to be susceptible to this disempowerment in the first place. If a cross-level, intersectional framework is kept in mind when designing DH interventions, they should gain more trust going forward.

Literature review

To place empowerment through mobile health applications in context, this literature review will first outline empowerment from its position within the broader climate of the democratisation of healthcare. I will then introduce the need for a multi-level and intersectional analysis of empowerment through DH. I will then put forward the 'RheumaBuddy' case study which will be used to elucidate the findings, and finally briefly describe the three ecological levels of empowerment within the context of this case study.

Empowerment and democratisation

Chronic illness puts an enormous burden not only on patients - but also on our healthcare systems, labour markets, benefit systems and informal carers (Lindsay & Vrijhoef, 2014). The 'empowerment' rhetoric stems from the current paradigm shift modern healthcare is experiencing through democratisation - referring to a rise in participatory, collaborate values within healthcare, where the top-down 'paternal' approach to health is shifting to the patient being the primary driver of health – a shift which Dickenson (2013) coined from 'we medicine' to 'me medicine'. While this is in attempt to improve patient outcomes, opting for 'prevention' rather than 'cure', it also stems from the position of our healthcare systems being overcrowded and in crisis.

The democratisation of health has two distinct goals from a public health perspective: bringing about empowerment through better health for patients, while unburdening healthcare systems and lowering costs simultaneously. The digital is arguably the primary mediator in this move from cure and compliance to care and empowerment, by giving patients the opportunity to develop into what Lupton (2013) dubs a 'digitally engaged patient': a patient who exudes high levels of self-efficacy and prioritises their health by being a knowledgeable, rational, active and ideal-patient citizen while utilising digital technology. Arguably, the neo-liberalist ideals which surround that of the 'digitally engaged patient' is problematic, as it privileges a micro-level perspective of empowerment (Lupton, 2016a).

The need for a multi-level analysis of empowerment

Aujoulat et al. (2007) discuss the 'polysemic' nature of empowerment. They describe it as a term with multiple meanings in different contexts – and a term that is not easy to define or apply in real-world situations. Logie et al. (2021) argue that, although the term is highly contested, it can be understood as a "non-linear, iterative and multi-level process". Patient (dis)empowerment should therefore not be viewed as an 'outcome' placed on either end of an extreme scale of empowerment versus disempowerment – but instead understood as an iterative 'process' in which patients weave

in between the two states as they navigate through their patient experience on micro (intrapersonal), meso (interpersonal) and macro (institutional) levels.

Solely viewing empowerment through the micro-level privileges neo-liberalist, Foucauldian autonomy and personal responsibility in the pursuit of self-care (El-Osta, 2019). Rejecting the idea of meritocracy in healthcare, it is understood that certain patients do not 'do better' in their experience of healthcare due to merit, effort or 'intrinsic' self-efficacy - but due to their position in the social world, and the relationships and structures influencing it. Anderson (1996) argues that 'unreflexive' use of empowerment within healthcare (which focuses on micro-level personal responsibility) ignores privilege. The role of social structures which hold power and perpetuate social inequities over marginalised individuals should not be ignored when considering patient empowerment through DH.

The intersectional feminist perspective

The ideal of the 'digitally engaged patient' that tends to surround patient empowerment through DH must also be situated within a framework of intersectional feminism. The concept of feminist intersectionality where public health is concerned seeks to highlight how the intersection of one subordinate identity (such as gender) with one or multiple other subordinate identities (such as race, socioeconomic status, and so on), result in distinct forms of marginalisation - which can catalyse through poorer health outcomes for those lying on one or more line of social disadvantage (Cuoto et al., 1994).

It can be argued that people who lie on limited intersections of inequality may be more likely to experience higher levels of patient empowerment, and at an easier rate, when compared to their marginalised counterparts. While intersectional feminism originates from theories of Black, indigenous, and Queer feminism (Sharma, 2019), it can be utilised in healthcare research to understand why certain individuals situated on different points of the 'Matrix of Domination' (Hill Collins, 1990) experience more (or less) difficulty in accessing (and embracing) high quality healthcare services.

An intersectional feminist perspective would align with Logie's (2021) multi-level analysis – and would seek to analyse how structural, interpersonal and intrapersonal dimensions of power are constructed, maintained, and resisted through multiple intersections of identity (Hill Collins, 1990). It is imperative to examine the relationships as a patient has which are marked by power and identity from the position of those who have systemically been excluded from power (Green, 2012). Applying this to DH is extremely relevant. DH has the opportunity to bolster equality: by giving easier and

increased access to health care, and through the empowerment of one's own health data. However, DH is rarely designed through a gender or racial equity perspective or with an intersectional framework in mind (Figueroa, 2021). In fact, it can be argued that DH is furthering levels of marginalisation for those who lie on intersections of inequality. This is due to exclusion from app design, gender imbalance in DH leadership, and harmful gender stereotypes (Figueroa, 2021). Computational and cognitive sciences, and thus DH in general, are built on a foundation of racism, sexism, colonialism, Anglo and Euro-centrism and white supremacy (Crenshaw 1981; Lugones, 2016; Birhane & Guest, 2020). For example, in the US, while 50% of the health-care workforce is female, there is a persisting gender gap in leadership positions. This is even wider in DH than in other fields (Rock Health, 2020).

Birhane & Guest (2020) have called for both a grass-roots and a top-down re-imagining of computational sciences, which champions a diverse demographic of researchers and actors to move away from a stagnant and marginalising ecosystem. Tackling DH's inequities is more crucial than ever (Figueroa, 2021). As a much larger and institutionalised issue, DH should strive for intersectionality as it has the potential to be the very route in which marginalised groups can be given the opportunity to gain further equality.

Case study: Why RheumaBuddy and RA?

RA is a rheumatic and musculoskeletal disorder (RMD), which are the most common chronic diseases in Europe (EULAR, 2020), affecting around 120 million people of all ages - one-quarter of Europe's population. The direct cost of RMD's within the EU is estimated at 240 billion euros per year, at 2% of its GDP (EULAR, 2020). RA poses significant health, economic, and social burden – however, it arguably is not considered an 'important' or 'high priority' disease when it comes to public opinion, health policy, or even research and scientific institutions - due to predominant focus being put on diseases and conditions with higher mortality rates. EULAR (2020) argues in their framework that RMDs are not receiving enough attention despite the extremely high rate of the diseases, and their high cause of economic and social fallout.

When considering the key goal of democratisation which is to improve quality of life while simultaneously unburdening patients and healthcare systems, RA is a disease which constitutes as highly relevant. According to Chahal et al. (2021), RA patients are increasingly interested in RA DH apps – however, adoption rates are low, and there is little research to date exploring the reasons behind this or exploring RA patient preferences when it comes to DH.

Utilising an intersectional feminist perspective in the study of RA is also highly relevant. There are large disparities in treatment outcomes and preferences for minority RA patients (Greenberg et al., 2013; McBurney & Vina, 2012, Constantinescu et al., 2019). While most of these papers focus on racial and ethnic disparities, it is also relevant when we consider any other intersection of inequality. This is especially important when we consider the fact that, for example, there are three times more women than men suffering with RA in Europe (EULAR, 2020), and 20 – 30% of RA patients become permanently ‘work’ disabled within three years of their diagnosis (Sokka, 2003).

The aim of the app Rheumabuddy is to support patients with self-management, with the goal of empowerment. While RheumaBuddy is the current award-winning market leader when it comes to digital RA management (Daman, 2022a), the self-tracking and empowerment narratives which underpin apps such as RheumaBuddy are increasingly being criticised in sociological studies. It is argued that the themes which arise in these studies, which I will now briefly outline and put into a cross-level context, are the reason why many seem to be disempowered, or simply indifferent (Lupton, 2013) when it comes to incorporating digital technology into their self-care regimes.

Applying a cross-level analysis

Micro-level

Firstly, the micro-level of empowerment is underpinned by neo-liberalist ideals and personal responsibility. It privileges a rational, self-motivated individual (Lupton, 2013), foregoing arguments surrounding the limits brought on by the intersectional disadvantages present in our social world on meso and macro levels.

Secondly, identity has a role to play on the micro-level. The present-day DH system has inherited our social world which is laced with biases and oppression. DH interventions created in this environment tend to work ‘better’ for those who fit the ‘default’ (Criado-Perez, 2019) - that is, members of an ecosystem which is home to, for the most part, a homogenous demographic of straight, white, able-bodied men.

DH needs to strengthen an individual’s sense of identity, not hinder it. It can be argued that technology acts under a system which oppresses due to its position of being created by (and tested on) for the most part individuals who lie on limited intersections of inequality (Figuroa, 2021). This raises interesting questions when you consider that data which is often skewed to perform better for certain individuals, can be privileged and given ‘technological authority’ (Sharon, 2016; Lupton, 2016a; Boyd and Crawford, 2012; Van Dijck, 2014) over the subjective ‘other’ experience (for example the experience of a woman, or the experience of someone who has a disability).

Meso level

The meso or 'interpersonal' level as described by Logie et al. (2021) is where we see negotiating and shifting power in relationship dynamics. This is relevant to DH when we consider: patient-HCP relationships; community relationships; and the human-digital relationship.

Patient empowerment could be seen to elicit power struggles within a patient-HCP relationship. This is especially important when we consider RA, as Barton et al. (2021) argue that there is disagreement on goal concordance between RA patients and HCPs in 1 in 5 cases. Within the rise of self-care and participatory values, the concept of the 'expert patient' (Shaw & Baker, 2004; Fox et al., 2005; Cordier, 2014) has emerged, and alongside it, connotations that it is a double-edged sword - in that it aids in the empowerment of patients, while often alienating medical professionals through a power struggle. The issue with an 'expert patient' which emerges through self-knowledge and being a member of online community groups such as that offered by 'RheumaBuddy' is that self-acquired, individual knowledge can be spread and used to understand a wider population even if it is not suitable in a show of 'psuedoexpertise' (Boulet, 2015). 'Expert patient' knowledge, although undoubtedly useful for the individual patient, is argued to be undermining HCP knowledge and could pose challenges between the HCP-patient relationship. However, perhaps the very hostility that the idea of an 'expert patient' brings about is contradictory to the ideals which underpin a democratised and participatory healthcare system – that is, patient-first solutions.

Acquiring social support is also a meso-level dimension of empowerment - and this affectively iterates from micro-level identity. It is important to recognise that behaviour within online communities is dependent on how related to a patient feels through their sense of identity, and the solidaristic trust which then stems from that (Jhao et al., 2013).

The relationship between patient and the digital is also relevant. This emerging relationship must be considered as the digital is not simply 'inanimate' (Lupton et al. 2018). The human relationship with data is referred to as 'human-data assemblages' (Marcus, 2016; Lupton, 2016b; Lupton, 2018; Zampino, 2019). When the digital is personified with 'liveliness' (Lupton, 2016a; Lupton, 2016b; Lupton, 2018) in this relationship, arguably there are new power dynamics and senses of meaning given to digital technology which need to be explored.

A patient must trust digital technologies for them to work (Stolz-Fink et al., 2015). There must also be a sense of mediation between the technology and the person – so that the patient does not feel overpowered by 'technological authority', and they still feel that sense of control - which is a key dimension to empowerment (Ouschan-Macrae et al., 2006; Aujoulat et al., 2008). The 'technological

authority' and control narrative raise interesting questions surrounding whether quantifiable, 'hard' data and datafication should be privileged over qualitative and subjective human experience. The conversion of 'subjective' aspects of health into 'black and white' quantifiable data through DH should be explored through a patient perspective. Perhaps an issue with patient empowerment is this privileging of technological authority as opposed to self-authority when it comes to understanding and comprehending health behaviours which are complex and subjectively human.

The 'playful' (Woodcock & Johnson, 2007) relationship that comes from the gamification of health is also relevant when considering DH. Patel et al. (2019) places gamification as the solution to empower disempowered patients through eHealth - when the advice from their HCPs and own 'good intentions' are not enough. This again reiterates to the micro-level when considering self-efficacy. It is interesting to explore whether those who are seen to lack the 'good intentions' as described here, are (in reality) those individuals suffering due to processes of oppression in our social world.

Macro level

The macro-level of empowerment is dependent on the transformation of structural and institutional systems (Logie et al. 2021). The shift seen within the democratisation of health places emphasis on patient consumerism and individualism – which Sharon (2016) argues undermines the very ideals of public health. Health under this paradigm can be envisioned as a 'choice' or a commodity in which to be 'earned', as opposed to understanding that an individual's health is dependent on their position in the social world. Crawford (1980) outlines the issues with this 'healthist' discourse, which is the idea that health is an individual's own responsibility – and should be ranked as the most important responsibility in life.

Empowerment under the democratisation of healthcare can arguably be synonymous with a disintegration of group responsibility for health (Sharon, 2016; Swan 2009; Lupton 2013). Less emphasis is placed on state or group responsibility for healthcare, and responsibility is instead emphasized into the hands of self-caring patients who are envisioned as rational, 'good citizens' (Lupton, 2016a). This again reiterates the privilege afforded to patients with high levels of self-efficacy seen on the micro-level.

Methodology

Procedure

This study followed the design of qualitative research case study, which is increasingly receiving recognition in health care research where social and cultural dimensions are concerned, through its humanistic and person-centred nature (Al-Busiadi, 2008; Renjith et al., 2021). The relationship between digital technologies and chronic illness patients was empirically analysed through an inductive approach – which recognised the problem of (dis)empowerment of patients using digital interventions and sought to create and test theories surrounding it. This case study focused on people with RA and Daman’s app ‘RheumaBuddy’. Phenomenology was used for methods of data collection and descriptive analysis, and Grounded Theory was used for methods of interpretation and theorisation, following from the example of Aujolat et al. (2008) in their qualitative study on patient empowerment.

The interviews for this research were divided into two parts and took place over two rounds. They were conducted alongside the UX designer at Daman. The first component of each interview was a usability test of a prototype of the new version of Daman’s app for RA - ‘RheumaBuddy 4.0’ - which is currently in redevelopment in anticipation of their clinical trial. The second part of the interview consisted of follow-up questions about the participants experience and expectations in general from the perspective of digital and health sociology. In the second round, we brought back two participants from the first round for follow-up interviews, with the aim of collecting more nuanced data and enhancing validity (Holter et al., 2019) after we had incorporated the user feedback from the first round into the prototype. 11 interviews with 9 people were conducted in total.

The interviews lasted between 60 and 90 minutes. They took place on Microsoft Teams. Online videoconferencing platforms are arguably rated above alternative interview mediums in health research (Archibald et al., 2019), and using this medium also allowed us to reach a more diverse sample to fulfill our inclusion criteria. As recommended in the tradition of phenomenological methodology (Ashworth, 1996; Moustakas, 1994), the interview guide and researchers avoided mentioning the term ‘empowerment’ or definitions close to it. However, due to some of the participants being well-versed in ‘expert’ patient jargon, they often brought the term up themselves. The interviews were recorded with the participants permission and transcribed before coding and analysis took place.

Following the key strengths of qualitative interviewing which are flexibility and responsiveness, each interview did not flow in the same direction, with participants weaving in and out of different topics as they deemed fit. Following an iterative approach, the interview guide was adjusted both following

a pilot interview (Kim, 2010) and depending on the way in which the conversation flowed. This went smoothly due to the participants being sent the interview guide prior to the interview taking place. They were then prepared to take lead in the conversation, and most areas were covered even though in an unstructured way. This is an example of a strength of collaborative, feminist research, which places the narrative created by the participant of the highest importance in the process.

Epistemological and theoretical approach

The epistemological stance for this study follows intersectional feminist methodology (Oakley, 1981; Stanley, 1996; Stanley & Wise, 1993; Campbell & Wasco, 2000; Hill Collins, 1990). This is due to narratives surrounding medicine, data science, and technology often being centred around whiteness, masculinity and able-bodiedness. The critical analysis of DH is best suited to be grounded in intersectional feminist thought. Daman's vision is in line with these intersectional feminist values – and to date have valued co-creation and collaboration between a variety of stakeholders, in particular patients (Daman, 2022b).

Social science research under a guise of 'objectivity', can cause more harm than good to those whose interests are in contradiction to hegemonic social orders (Dei & Asgharzadeh, 2001). Therefore, my epistemological stance will not be hidden under a guise of 'objectivity'. Qualitative research demands reflexivity throughout the process, and a key factor of this is paying attention to researcher positionality as opposed to ignoring it (Srivarathan, 2021). The 'felt necessity' of this research will be understood through the researcher's position in having a chronic illness, so having an eagerness to learn more about the relationship between chronic illness and DH in line with an attempt to overcome what Stanley (1996) coined 'crises of representation'. This is relevant for a lot of the team at Daman – where employees often resonate with the vision of the company through themselves or family members also experiencing chronic illness. The position of this work being for Daman, the main stakeholder when it comes to 'RheumaBuddy', was also taken into consideration.

Participants

The inclusion criteria for participation in this study was adults aged 18+ with RA in Europe who were happy to conduct an interview through English. Participants were recruited through Daman's co-creation network; RheumaBuddy's userbase; and patient organisations of the three respective countries: NRAS (UK), Arthritis Ireland, and FNUK (Denmark). Participants were purposively sampled to strike a balance between different socioeconomic, clinical and psychological variables, which were: age, gender, location, income, educational status, employment status, clinical status, and length of diagnosis. The breakdown of participants is listed in Figure 1. The aim of creating a diverse

sample, although excluding the race variable, was to give an opportunity to glean insights into the intersectional level of RheumaBuddy and other alike DH platforms - and how this may be affecting their users (dis)empowerment, or otherwise.

Figure 1: Participant breakdown

Participant	Gender	Age	Location	Self-reported Income	Clinical Status	YRs since diagnosis	Higher level Education	Employment Status
Christina	Female	63	UK	Mid	Good	6	Yes	Medically retired
Pia	Female	27	DK	High	Up & down	24	Yes	Employed
Sally	Female	45	UK	Low	Remission	30	No	Unemployed
Jane	Female	67	UK	Low	Working on it	1	Yes	Employed
Mary	Female	63	IRE	Low	Up & down	17	No	Unemployed
Lena	Female	26	DK	Low	Good	1	No	Unemployed
Will	Male	43	DK	Low	Struggling	5	Yes	Flex job
David	Male	38	UK	High	Not controlled	8	Yes	Employed
Frank	Male	67	UK	Low	Good	35	Yes	Retired

Coding and analysis

The research design will draw from qualitative thematic analysis techniques. Using the iterative framework for interpreting qualitative data outlined by Kekeya (2016) and under Grounded Theory processes, I began by organising the data, which began once the first interview was completed. I used thematic and narrative analysis to generate meanings from the data using an intersectional and cross-level framework in mind. I created units of meanings, representing overarching themes, and they were understood through generated codes (Sarantakos, 2005) which I tagged into the data - for example 'CS' for 'Community Support'. All participants were assigned pseudonyms for analysis.

As it was a multi-level analysis, the findings were broken down into micro, meso and macro levels, taking inspiration from previous studies (Logie et al, 2021; Winker & Degele, 2011). The micro, meso and macro levels of empowerment became the three overarching themes to illuminate the experience of patient empowerment through DH. These dimensions were then made sense of against my literature review in order to create a wider understanding of the topic at hand, and to give a solid grounding for the importance of utilizing a multi-level and intersectional feminist approach when analysing the level of patient (dis)empowerment through DH technology going forward.

Findings

Micro-level empowerment

At the micro level, individual and personal features such as identity and agency highly influenced patient empowerment, and the digital constituted as a highly valuable enabler for the strengthening of these intrapersonal factors.

Agency

Participants were aligned in their perception that without agency and high levels of self-efficacy, patients would struggle with empowerment. DH applications promoted agency by acting as a motivating catalyst for behaviour change. Will believed apps could “remind people that they can do something for themselves to get better”, and Mary appreciated apps “prompting you” and “motivating you to reach targets”. However, these nudges and targets could become disempowering and potentially lacking in empathy, when “you are feeling low or tired, and you just don’t have the motivation to do it” (Jane). When you were in a poor mental or physical state, apps could either “give you a kickstart to get going” (Christina) or elicit feelings of guilt and inadequacy when they remind you of the things you ‘should’ be doing in an environment privileging healthist ideals.

Agency was perhaps seen as a dimension of empowerment which lacked a holistic understanding of the “bigger picture that is living with a chronic illness” (Pia). It was not always as simple as “get(ting) up and do(ing it)” (David), as the “confronting” (Pia) and “overwhelming” (Jane) nature of DH interventions were often too much to deal with if you were not that rational, ideal and ‘expert’ patient with high levels of ‘intrinsic’ self-efficacy as theorized by Lupton (2013). Will highlighted the need to consider mental health when positioning the digital as this ‘ideal enabler’ when it came to motivating patients:

“When I was low, would it have worked? No. I was at a stage where self-empowerment is not important, because I can’t do anything about it anyway. I could probably die. And that’s the really dark, black thinking here. When you get into the stage of acceptance, but you are not necessarily proactive yet, this will help you get into that stage earlier. But will it do something for me while I am in a bad state? No. It depends on the mental state of mind”.

Identity

When considering identity on a micro-level, participants were disempowered when there was a lack of a recognition towards complex and individual needs, and when ‘normative’ features in apps were of a one-size-fits all model. ‘Generalised’ features were immediately rejected and labelled as

‘undermining’ or ‘annoying’, and responsible of highlighting to the participants of “just the things I can’t do” (Christina). An example of this came from Sally, a wheelchair user, who highlighted the tendency of DH apps to be ableist:

“I know that I don’t have to do 10,000 steps to be ‘good’, or whatever, but there is still that subliminal expectation that you should be doing 10,000... and it is not nice to always have a feeling of being inadequate...”

Sally’s allusion to Fitbit causing her to feel ‘inadequate’ due to being chronically ill and disabled points to the need for healthcare apps to ensure inclusivity across the board. This was also highlighted by Will, who had RA in his wrists, and therefore could not use a wearable fitness tracker (like many others with RA), and therefore needed alternative measures in order to be able to passively track data. He felt this was often overlooked in DH design. DH apps were empowering when they accounted for different identities and abilities:

“whereas this, (RheumaBuddy), it just feels safe. The expectation of being really physically fit isn’t there. Whereas Fitbit is aimed at... normal? You know what I mean... normal people”. Sally

Frustration with the ableist and ‘normative’ features of DH interventions that were “not accessible to everybody” (David) was felt by all participants, particularly in their mutual rejection of a ‘RheumaBuddy’ prototype feature which recommended users to ‘take a walk with friends or family’. The ableism of this recommendation was made evident by the fact many people with RA cannot walk the same type of routes, or at the same pace, as people without RA. Psychologically, it also highlighted the potential loneliness of participants who felt they did not have family or friends to walk with. Frank also spoke about the importance of ensuring the interface had “colours and symbols” due to people with dyslexia and other issues with technology. The use of non-inclusive features and language, as well as negative generalisations and stereotypes, were issues highlighted time and time again as disempowering by the participants, as they only exacerbated feelings of difference and disability:

“People have this general idea in their head... and it is just put out constantly. The general only works if you are fine and physically healthy”. (Mary)

Meso-level empowerment

At the meso level, participants spoke widely on the different types of interpersonal relationships that affected empowerment, and how DH apps like ‘RheumaBuddy’ were influencing these relationships. There were three relationships that shone through as being the most important: a community relationship; a patient-HCP relationship; and a human-digital relationship.

Community relationship

The opportunity that the digital brought in terms of community-building and knowledge-sharing was highly valued by the participants and deemed imperative when it came to gaining empowering experiences. Community support groups, such as the community feature offered by 'RheumaBuddy', were trusted to very high extents by all participants and gave rise to high levels of solidarity. Will spoke about his experience in sharing advice within communities with other people with RA and what it did for him:

"Helping others was my support to myself. That was my self-empowerment".

Being a member of a patient community with a shared identity (such as having RA) gave the participants that confidence to become an active participant in healthcare and act out as that 'expert patient'. Seeing other peoples "lived experience" (Frank) within a community and gaining that sense of solidarity ensured patients were not passive participants alongside their HCPs in decision-making, as explained by Frank:

"Sometimes you feel different to what the consultant says. At first you think, 'it must just be me' or that you're wrong. But when you talk in the community, you realise it isn't just you after all, and you were maybe putting yourself down a bit. The community experience is terrific because without it you might get the idea that you've just got to put up with it. The community is reassuring. It reaffirms you are one of a group. A medical opinion is called a medical opinion, and that is what it is. You can ask for other opinions".

However, following from the micro-level conflict surrounding identity, if you did not "fit the stereotype of someone who is expected to have RA" (David) these community groups could sometimes be stereotypically viewed as "knitting clubs", and lead to disempowerment. If patients did not align with the 'stereotype' of someone you would expect to have RA (which tends to be elderly women), these groups contributed to an erosion to their identity as a patient with RA. This conflict within RA communities was felt by Sally:

"I've gone in and out of really wanting to connect with other people with RA really, and then it getting a bit too much... I think it is because I am at the severe end of the spectrum sometimes... it is hard to get that level of understanding".

Digitally enabled community support held that dualistic nature of both being empowering and disempowering depending on an individual's personal experience and situation. Sometimes participants felt they simply did not fit in within support groups, and some (such as Pia) were "not interested in learning how other people feel" through community groups because they just

reminded them “that they were sick”. The disempowerment felt at the micro-level is affectively iterated to the meso-level, in a rejection of the community support you are allegedly supposed to share solidarity with.

Digital relationship

A stable digital-human relationship or ‘assemblage’ was also important when considering meso-level dimensions of patient empowerment through DH. As mentioned in the literature review, the digital should not be viewed as inanimate. It was clear that (dis)empowerment was felt by participants depending on the type of relationship and trust levels they developed with apps such as ‘RheumaBuddy’, and the data in which they produced. Frank spoke about his preference for a health app to be a “friendly, chatty sort of thing”, and Jane spoke about needing a “digital ‘buddy’ for the support”.

Trust in the digital to work as it is supposed to, and provide credible and validated feedback, was vital for an empowering relationship with it. David spoke negatively about the “subjective” nature of self-reporting as opposed to the “real, substantive data” you would get with a digital tracker. For example, he would always trust the information from data even if it didn’t align with how he ‘felt’ - privileging data over subjective human experience. This points to the high levels of trust afforded to data by certain participants, including Will, who didn’t like the idea that he could ‘edit’ data (for example editing steps counted by the devices step counter). He posed that this would only lead him to “cheat”.

Contrarily, it seemed other participants in different social contexts often found themselves questioning the data they produced if it did not match up to the way in which they subjectively ‘felt’. Sally spoke about her Fitbit consistently getting her sleep data wrong, putting it down to her HR being very low when she is in a lot of pain. Christina believed she would “easily trust the app (RheumaBuddy) because it is my own data I am entering”, alluding to lower trust levels from data which is passively tracked. For some participants, self-reporting data and the ability to edit this data was important – especially due to the belief that the digital can sometimes get it ‘wrong’. For others, arguably those on limited intersections of inequality, it seemed they had more trust in the digital as opposed to themselves.

Participants were divided about the use of gamification (for example, using smiley emoticons to rate symptoms; or the ‘buddy’ element) in healthcare apps. On the one hand, participants spoke about being “used to it” (Lena) because elements such as these are “widespread in all ways of life” (Frank) and “just our world now” (Jane). However, despite being ‘used’ to it, David spoke about his perhaps

demeaning or disempowering experience dealing with measures such as these in clinical appointments:

“The Smileys always surprised me. When I went to the rheuma’ consultant for the first time, they gave me a sliding ruler that had a smiley face scale on it... and I was 30 years old. I was like what is this, what, what. And then on the back of it, there was all weird mathematical scores that gave me my DAS score. It’s like, I’m here for a medical treatment. I don’t want to be pointing to smiley faces”.

Participants such as David reaffirmed the notion from Woodcock & Johnson (2017) that some disciplines in life “are not, and never will be, playful”. Although gamification measures were criticised, there was a consensus that they ‘made sense’ and were ‘easy’ - and alternatives with which to replace them were not offered by the participants. The stark dualism of this feature is shown particularly when considering Jane and Sally, who “absolutely love” (Jane) emoticons to rate symptoms, and “get very excited” (Sally) when digital health apps reward them for reaching goals. However, the perhaps juvenility was still highlighted by Sally, who felt it was “ridiculous how you go back to being a child, or a ‘good girl’”.

The quantification of self was also criticised. Participants felt “forced” to choose numbers that “don’t really reflect how you are” (Christina) and felt vagueness surrounding the distinctions from one quantified data point to the next:

“What is the difference between a 6 and a 7? What is that really telling you?” (Christina)

However, participants appreciated the simplicity and easy-to-compare nature of quantifiable, numerical data points - highlighting its duality. Where Will thought numbers were “boring” and argued there are “so many other nice ways to represent things other than numbers”, Pia spoke about needing “factual checkpoints” as opposed to using smileys or “loose” qualitative measurement points (such as ‘good’ or ‘bad’ in the case of measuring sleep). Lena also appreciated ‘hard’ data:

“I do like the concept. I’m black and white. I like numbers... statistics... I like facts”.

HCP relationship

A mutually respected relationship between patient and HCPs was key to patient empowerment for the participants. A patient-HCP relationship which was marked by democratisation and shared-care values ensured that patient control and patient power in decision-making processes was made a reality.

However, few of the participants had experienced a patient-HCP relationship which prioritised active patient participation under a democratic approach, and instead insisted that if they had it, they had to 'fight' for it:

"They talk a lot about holistic care, about shared care, I am just going to say it straight... because it just doesn't happen. When you challenge them, they don't like it. They don't really like giving that level of control back to you... So now I do everything I can to manage my appointment. I don't let her (doctor) interrupt. I don't let her take control. If she does interrupt, I'm very straight with her, I say 'excuse me doctor, but you're actually interrupting me again'" (Christina)

This lack of opportunity for shared decision-making was seen to be down to a variety of factors - ranging from sheer lack of time in appointments, to deeper rooted perceived 'power struggles' and a perceived lack of trust from HCPs in sharing that power and control. Frank spoke about how you "have to speak up" and alluded to the patients who did not necessarily have the confidence to do so (on a micro-level) suffering as a result, through 'generalised' treatment of a highly individual disease. It seemed as if the patients were not encouraged to be involved in shared decision making, but it was possible if hard work was put in by the individual patient to get there – highlighting again the privileges afforded to those 'expert patients' with high levels of self-efficacy on a micro-level.

The role of data-tracking through DH enabled the participants to gain the credibility needed from HCPs in order to be 'trusted' to participate in decision-making. Participants spoke about having data on an app act as 'proof' of certain health trends, which aligned with the idea that your knowledge is more 'valid' when 'datafied' and digitised as opposed to relying on the 'vagueness' of human subjectivities (Sharon, 2016; Lupton, 2016a; Boyd and Crawford, 2012; Van Dijck, 2014). The digital acted as the mediator between patient and HCP - strengthening the levels of trust afforded to patients to *actually engage* in shared decision-making. This patient-credibility was generated through the confidence that came with increased self-knowledge, as well as the 'proof' of proactivity and self-care values that data-tracking brought. Interestingly, Will and David spoke about how they do not track for their own self-knowledge, but in order to gain that credibility and provide 'proof':

"It is very important that the patient takes that responsibility over their own disease. But to do that convincingly, they (HCPs) would have to know that I know more about my illness myself before I go to see them. The app gives me the opportunity to show that" Will

"You can hobble in, you can struggle to open the door to the consultation room, all that. But is that enough evidence to back you up? No. They just go, you're probably playing it up 'cause you want

something else at the moment. But if you have stuff in the diary (app), you've got results and records to back you up" David

The role of the digital to 'back you up' again points to the notion that digitized knowledge is perceived as more 'valid' when it comes to the 'proving' of health trends, especially when it comes to doing so with perceived 'sceptic' HCPs.

It was clear that the ideal patient-HCP relationship was made a reality through digital mediation: firstly, through increasing self-knowledge for the participants, and secondly, through then 'proving' to their HCPs that they were capable or 'deserving' of engaging in power sharing, by providing quantifiable 'proof' that HCPs could easily engage with.

Macro-level empowerment

At the macro level, empowerment through DH was strengthened due to the structural paradigm shift taking place under the democratisation of healthcare – and the digital aided in ensuring this paradigm shift took place smoothly. Digital apps were seen as the way in which to gain that bigger picture and more holistic overview of your entire health, both mental and physical. A patient could then prioritise what they thought was important to them in an effort of self-care, and then have the data to back up that importance in clinical appointments to engage in shared decision-making and contribute to this paradigm shift:

"The patient doesn't care about the blood tests or the results they measure. No, I don't care if my bloods are a 10, or a 5, whatever. I want to experience a better life. You can't read that out of a blood test". David

"No matter how blood results etc. appear, if you don't feel good, something is not right. The apps should help identify that". Frank

When shared decision-making and the patient-credibility that comes with it was not prioritised by HCPs, higher levels of disempowerment were clearly seen through frustration, disappointment and feelings of helplessness. When patients did not feel trusted to "know themselves and know their bodies" (Christina), they had to spend extra energy and emotional labour 'fighting', or 'exaggerating'. For example, in the case of Pia, who "always put 10% on top" so her doctor would "take her seriously". David voiced his frustration on how it was perceived to be engaging in decision-making as an active participant under this macro-level paradigm shift:

"We should be allowed and encouraged to challenge the decisions that doctors make. And I think quite often people see it as a fight when you go to the hospital to speak to the doctors about stuff... why is it like that? It shouldn't be a fight."

It was clear that patients sometimes did not feel trusted by HCPs to act out as the 'expert' patients they saw themselves as. Will highlighted the idea that, although there is a clear "paradigm shift where patients are getting more involved"... "the discourse between patients and HCPs are still very much not aligned". It is contradictory in terms to the very ideals which underpin democratisation and shared-care values, where public health experts envision this structural shift as the way in which we deal with an ageing population and rise of chronic illness.

Where Sharon (2016) would critique democratisation as "masking a dynamic of abandonment rather than empowerment", contrarily every participant highly valued ideals of self-care and understood and accepted the 'paradigm shift' that was taking place within the democratisation of healthcare. There was consensus that each participant was their "own number one supporter" (Christina) and you could "figure it all out on your own" (Lena). It was disempowering when self-care was not prioritised in the care-continuum, especially for Lena, who does not "like the concept of having to be taken care of".

While also alluding to the commodification of health, Frank argued that you must "buy into your own health and not expect everyone else to do something for you". Jane even believed having a large network to support her in her care, instead of majorly relying on self-care, could be an "excuse to get lazy". The collective responsibility for health that underpins the idea of being 'taken care of' and having others 'do something for you' was, interestingly, framed negatively and as markers for laziness by the participants. Democratisation and the ideals which underpin it was, for the most part, framed in empowerment terms.

It was clear the digital was allowing for a softer emphasis on 'abandonment' in self-care in this democratized system, and acting as that missing support piece in place of traditional top-down and community support:

You have got to look after yourself... and I think it is the lack of extended families making it hard... because people move out (of one built-up area) and they are scattered... that is what apps are going to give to me. Apps are going to be that extra level, giving that extra support we have lost" Frank

However, the top-down and self-imposed pressure surrounding self-care was also highlighted, and could be perceived as disempowering, however necessary, when it comes to self-care. Frank posited feeling like a "failure if you can't do it", and highlighted the mental stress felt when "your brains says to do it... but the body is saying give me a break". Jane spoke about the pressure to look after herself "just because now I am sick", alluding to the higher expectations of 'healthism' placed on those with chronic illness.

Will compared the strain of self-care to “plow(ing) until I hit a brick wall... but I just get up and I do it. I have to”. This rhetoric surrounding lack of choice points to the burden surrounding the necessity of self-care - which is unwittingly placed upon people with chronic illness amongst all their other responsibilities in the context of democratized healthcare:

“You have already got to keep track of your life more when you have a chronic illness... this (digital app tracking) on top of it is a hassle”. Lena

Interestingly, Frank (from the UK) also spoke about how self-care is “not just empowering... it is crucial financially”. This was like Mary (from Ireland) who “place(s) a lot of pressure on self-care... because everything (healthcare) just costs so much money”. For her, you are “gaining in the area of data what you are lacking from the medical side”. This contrasts with Will (from Denmark), who despite describing himself as having a low income, described his life in terms of finances as relatively ‘easy’ and put it down to the Danish welfare state:

“I have a low income. But I drive a BMW, I have a big house, I don’t clean my own clothes, I don’t do any cleaning... I must say the welfare system here in Denmark is more on above what you can expect, really”.

It is interesting that participants from the two countries with lower levels of social welfare (compared to Scandinavian Denmark) placed self-care as paramount in relation to saving them from being ‘abandoned’ by their respective country’s welfare states.

Limitations

This study encountered a range of limitations that were anticipated before the process began and reiterated as the process proceeded. One limitation was not including race as a variable. The original research proposal and hypothesis which aimed to focus specifically on the factors of race and gender influencing empowerment was reshaped to align with Daman's specific research focus and agenda.

A second limitation relates to the size of the sample recruited. Only 9 participants were recruited for this study, which affects its external validity (Faber & Fonseca, 2014). Unfortunately, it was difficult to recruit a wide range of participants for this study, particularly as the research was for Daman, a profit organisation. This may reflect the lack of trust shown by patients in digital health corporations when it comes to data exploitation (Adjekum et al., 2018).

Lastly, due to the recruited participants being arguably more 'active' and 'participatory' in their care, and perhaps more technologically advanced than the 'average' patient (just by virtue of signing up for this research in the first place), there is an awareness that they can be perceived as the 'ideal' type of participant. Despite creating a diverse sample, the participants were nonetheless quite specific in some of their characteristics and therefore held corresponding viewpoints which may not always hold true in the general population - which may contradict the very ideal of intersectionality which underpins the goal of this research. I have addressed this throughout, highlighting the position of some of the participants as 'expert patients'.

Assumptions are made, as described by the participants, about perhaps an alternative patient or a 'younger version of themselves' who would not fit into this 'ideal' type – however, generalisations should not be made based on this small sample. This reflects issues seen time and time again in research and clinical trials in general (Varma et al., 2022; Mitra-Majumdar & Kesselheim, 2022; Niranjana et al., 2020) - where people who 'sign up' to engage in such research tend to lack heterogeneity in the way they may experience the social world or the topics of interest. This is an issue that must be addressed in research going forward.

Discussion

The importance of recognizing the “non-linear, iterative, and multi-level” process of empowerment (Logie et al., 2021) through DH and not privileging the ‘self-efficacy’ associated with the micro level is one of the key findings from this research. The perceptions surrounding agency and ‘intrinsic’ self-efficacy as associated with micro-level empowerment were not cognizant of the nuances associated with the true lived experience of chronic illness for the participants, often foregoing issues relating to mental health or an individual’s position in the social world.

The different ecological levels of DH empowerment were interlocking and all highly influencing each other - for example, comments intertwining identity and community alluding to the multi-level impact that an eroded identity on a micro-level has. Arguably, this was most prominent when considering the macro-level dimension surrounding democratisation: democratisation was only empowering when the micro and meso level dimensions were accounted for. You cannot transform the structural paradigm of healthcare and expect patients to be willing, and able, to simply conform – without considering the multitude of factors.

As illuminated by the participants, empowerment came through agency; a strong sense of identity; strong interpersonal relationships between other patients, HCPs, and the digital devices they were using; and the structural reorganization of modern healthcare values. Participants had to experience high levels of trust across all these domains in order to be empowered through DH. Following from this, I argue that a cross-level and intersectional feminist approach should be utilized within DH going forward, in order to gain higher levels of trust; bolster inclusion; and enable empowerment rather than abandonment.

Bolstering inclusion

The participants placed a sharp emphasis on the heterogeneity between people with certain chronic conditions – and the importance of not putting patients in a box just because they happen to share the same illness. As previously mentioned, it was clear that there was a role for DH interventions to bolster inclusion – however, to do so they need to be designed with an intersectional feminist framework in mind. The participants situated on intersections of inequality could not gain empowerment through generalized treatment plans created from the blueprint of those who are situated on limited intersectional of inequality. If not accounting for the range of identities and abilities, they became disempowering.

The complexity of the ‘double-face’ and dualism of empowerment also shines through when we consider that each individual patient will have a different perception on what is and what is not

empowering for them personally (Aujoulat et al., 2007). For example, while some patients may find solidaristic empowerment in engaging with community support networks, others will simultaneously find this disempowering – as perhaps it may overly confront them with their disease status or bring up intrapersonal conflict relating to identity.

Trust

When DH interventions recognized intersectional identity, they became easier to trust and relate to for the participants. When there were higher levels of trust, patients were more likely to adhere to the recommendations put forward by the interventions, and therefore experience more empowering experiences. Participants felt trust with DH when they felt recognized and listened to as people, and not just ‘patients’. It is important to highlight the ability of co-creation to highlight the nuances associated with the lived patient experience - and to then create solutions that *actually* work. Under an intersectional feminist epistemology, giving a voice to those who are often excluded from decision-making is key to the empowerment of patients using DH.

Empowerment over abandonment

It was clear that under the democratisation of healthcare, the digital was the mediator to ensure patients were not ‘abandoned’ (Sharon, 2016). However, it was clear that for different patients, different mediation techniques had to be employed to ensure the digital did not hold power and control over the patients. Patients situated on intersections of inequality had to learn to put trust in self as opposed to trust in the system that oppresses them – by accepting the fact that the digital could sometimes ‘get it wrong’ due to often being tailored to work for the ‘default’. This mediation was imperative to experience empowerment through DH for individuals lying on intersections of inequality. There is arguably a clear role for the digital here to be that self-care mediator and offer that support which is lacking due to failures in healthcare systems.

Reference list:

- Adjekum, A., Blasimme, A., & Vayena, E. (2018). Elements of Trust in Digital Health Systems: Scoping Review. *Journal of medical Internet research*, 20(12), e11254. <https://doi.org/10.2196/11254>
- Al-Busaidi, Z. Q. (2008). Qualitative research and its uses in health care. *Sultan Qaboos Univ Med J*, 8(1), 11-19. <https://www.ncbi.nlm.nih.gov/pubmed/21654952>
- Anderson, J. M. (1996). Empowering patients: Issues and strategies. *Social Science & Medicine*, 43(5), 697-705.
- Archibald, M. M., Ambagtsheer, R. C., Casey, M. G., & Lawless, M. (2019). Using Zoom Videoconferencing for Qualitative Data Collection: Perceptions and Experiences of Researchers and Participants. *International Journal of Qualitative Methods*, 18. <https://doi.org/Artn 1609406919874596>
- Ashworth, P. (1996). Presuppose nothing! The suspension of assumptions in phenomenological psychological methodology. *Journal of Phenomenological Psychology*, 27(1), 1-25.
- Aujoulat, I., d'Hoore, W., Deccache, A. (2007). Patient empowerment in theory and practice: Polysemy or cacophony?. *Patient education and counselling*, 66, 13-20. 10.1016/j.pec.2006.09.008
- Aujoulat, I., Marcolongo, R., Bonadiman, L., & Deccache, A. (2008). Reconsidering patient empowerment in chronic illness: A critique of models of self-efficacy and bodily control. *Social Science & Medicine*, 66(5), 1228-1239.
- Barton, J.L., Markwardt, S., Niederhausen, M., Schue, A., Dougherty, J., Katz, P., Saha, S. and Yelin, E.H. (2022). Are We on the Same Page?: A Cross-Sectional Study of Patient-Clinician Goal Concordance in Rheumatoid Arthritis. *Arthritis Care & Research*. Accepted Author Manuscript. <https://doi.org/10.1002/acr.24794>
- Birhane, A., Guest, O. (2020). Towards decolonising computational sciences. *Kvinder, Køn & Forskning*, 29, 60-73
- Boulet, L. P. (2015). The Expert Patient and Chronic Respiratory Diseases. *Canadian respiratory journal*, 2016.
- boyd, d., Crawford, K. (2012). Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon. *Information, Communication & Society*, 15(5), 662-679.
- Campbell, R. and Wasco, S. (2000). Feminist Approaches to Social Science: Epistemological and Methodological Tenets. *American Journal of Community Psychology*, 28(6), 773-791.
- Chahal, S., Biln, N., Clarke, B. (2021). Patient Perspectives on a Digital Mobile Health Application for RA. *Open Access Rheumatology: Research and Reviews*, 13, 63.71.
- Constantinescu, F., Goucher, S., Weinstein, A., Smith, W., & Fraenkel, L. (2009). Understanding Why Rheumatoid Arthritis Patient Treatment Preferences Differ by Race. *Arthritis & Rheumatism- Arthritis Care & Research*, 61(4), 413-418. <https://doi.org/10.1002/art.24338>
- Cordier, J., (2014). The expert patient: towards a novel definition. *European Respiratory Journal*, 44(4), 853-857.
- Couto, M. T., de Oliveira, E., Separavich, M. A. A., & Luiz, O. D. (2019). The feminist perspective of intersectionality in the field of public health: a narrative review of the theoretical-methodological literature. *Salud Colectiva*, 15. <https://doi.org/ARTN e1994>

- Crawford, R. (1980). Healthism and the medicalization of everyday life. *International Journal of Health Services*, 10(3), pp. 365–388
- Crenshaw, K. (1989). Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics. *University of Chicago Legal Forum*, 1(8).
- Craido-Perez, C. (2019). *Invisible Women: Exposing Data Bias in a World Designed for Men*. New York: Abrams Press.
- Daman (2022a). Retrieved 15 June 2022, from <https://www.damandigital.com/projects>
- Daman (2022b). Whitepaper: Co-creation in healthcare.
- Dei, G. J. S., & Ashgarzedah, A. (2001). The Power of Social Theory: The Anti-Colonial Discursive Framework. *The Journal of Educational Thought (JET) / Revue de La Pensée Éducative*, 35(3), 297–323.
- Dickenson, D. (2013). *Me Medicine vs. We Medicine: Reclaiming Biotechnology for the Common Good*. New York: Columbia University Press.
- Drury, J., Evripidou, A., Van Zomeren, M. (2015). “Empowerment: The Intersection of Identity and Power in Collective Action”. *Power and Identity*. Psychology Press.
- El-Osta, A. (2019). The Self-Care Matrix: a unifying framework for self-care. *International Journal of Self Help and Self Care*, 10(3), 38-56.
- EULAR (2020). Horizon 2020 Framework Programme: EULAR’s position and recommendations. Eular Brussels Office: Brussels.
- Faber, J., and Fonseca, L. M. (2014). How sample size influences research outcomes. *Dental press journal of orthodontics*, 19(4), 27–29. <https://doi.org/10.1590/2176-9451.19.4.027-029.ebo>
- Figueroa, C. A., Luo, T., Aguilera, A., & Lyles, C. R. (2021). The need for feminist intersectionality in digital health. *Lancet Digital Health*, 3(8), E526-E533. [https://doi.org/10.1016/S2589-7500\(21\)00118-7](https://doi.org/10.1016/S2589-7500(21)00118-7)
- Fox, N., Ward, K. and O’Rourke, A. (2005). The ‘expert patient’: empowerment or medical dominance? The case of weight loss, pharmaceutical drugs and the Internet. *Social Science & Medicine*, 60(6), 1299-1309.
- Green, B. (2012). Applying Feminist Ethics of Care to Nursing Practice. *Journal of Nursing and Care*, 1(3). DOI: 0.4172/2167-1168.1000111
- Greenberg, J. D., Spruill, T., Ogedebe, G., Kremer, J. M., Shan, Y., Saunders, K. C., Yazici, Y., & Harrold, L. R. (2012). Racial and Ethnic Disparities in Rheumatoid Arthritis Outcomes in Community-Based US Rheumatology Practices: Results From the Consortium of Rheumatology Researchers of North America Registry. *Arthritis and Rheumatism*, 64(10), S905-S905. <Go to ISI>://WOS:000309748305058
- Henwood, F., Marent, B. (2019). Understanding digital health: Productive tensions at the intersection of sociology of health and science and technology studies. *Sociology of Health & Illness*, 41, 1-15. <https://doi.org/10.1111/1467-9566.12898>
- Hill Collins, P. (1990). ‘Black Feminist Thought in the Matrix of Domination’. In: *Black Feminist Thought: Knowledge, Consciousness, and the Politics of Empowerment*. Boston: Unwin Hyman, pp.221-238.

- Holter, M. T., Johansen, A. B., Ness, O., Brinkmann, S., Høybye, M. T., & Brendryen, H. (2019). Qualitative Interview Studies of Working Mechanisms in Electronic Health: Tools to Enhance Study Quality. *Journal of Medical Internet Research*, 21(5), [e12054].
<https://doi.org/10.2196/10354>
- Zhao, J., Abrahamson, K., Anderson, J.G., Ha, S., & Widdows, R. (2013). Trust, empathy, social identity, and contribution of knowledge within patient online communities. *Behaviour & Information Technology*, 32(10), 1041-1048. DOI: 10.1080/0144929X.2013.819529
- Kaldoudi, E., Makris, N. (2015). Patient Empowerment as a Cognitive Process. In: C. Verdier, M. Bienkiewicz, A. Fred, H. Gamboa and D. Elias (Eds.), *The Proceedings of HealthInf 2015: 8th International Conference on Health Informatics*, pp. 605-610, Lisbon, Portugal, 12-15 January, 2015 (ISBN: 978- 989-758-068-0).
- Kekaya, J. (2016). Analysing qualitative data using an iterative process. *Contemporary PNG Studies: DWU Research Journal*, 24, 86-94.
- Kim, Y. (2010). The Pilot Study in Qualitative Inquiry. *Qualitative Social Work: Research and Practice*, 10(2), 190-206.
- Lindsay, S., Vrijhoef, H.J.M. (2009) A sociological focus on 'expert patients'. *Health Sociology Review*, 18(2), 139-144, DOI: [10.5172/hesr.18.2.139](https://doi.org/10.5172/hesr.18.2.139)
- Logie, C. H., Earnshaw, V., Nyblade, L., Turan, J., Stangl, A., Poteat, T., Nelson L., Baral, S. (2021): A scoping review of the integration of empowerment-based perspectives in quantitative intersectional stigma research. *Global Public Health*. 10.1080/17441692.2021.1934061
- Lugones, M. (2016). The coloniality of gender. *The Palgrave Handbook of Gender and Development*, 13–33.
- Lupton, D. (2013). The digitally engaged patient: Self-monitoring and self-care in the digital health era. *Social Theory & Health*, 11(3), 256-70. <https://doi.org/10.1057/sth.2013.10>
- Lupton, D. (2014). Beyond Techno-Utopia: Critical Approaches to Digital Health Technologies. *Societies*, 4, 706-11.
- Lupton, D. (2016a). *The Quantified Self*. Cambridge: Polity.
- Lupton, D. (2016b). Digital companion species and eating data: Implications for theorising digital data–human assemblages. *Big Data & Society*, 3(1), 1-5.
- Lupton, D. (2018). How do data come to matter? Living and becoming with personal data. *Big Data & Society*, 5(2), 1-11.
- Lupton, D., Pink, S., Labond, C., Sumartojo, S. (2018). Personal Data Contexts, Data Sense, and Self-Tracking Cycling. *International Journal of Communication*, 12(2018), 647–665.
- Marcus, G., (2006). Assemblage. *Theory, Culture & Society*, 23(2-3), pp.101-106.
- McBurney, C. A., Vina, E. R. (2012). Racial and Ethnic Disparities in Rheumatoid Arthritis. *Current Rheumatology Reports*, 14(5), 463-471. <https://doi.org/10.1007/s11926-012-0276-0>
- Mitra-Majumdar M., Kesselheim A.S. (2022). Reporting bias in clinical trials: Progress toward transparency and next steps. *PLOS Medicine* 19(1), e1003894.
<https://doi.org/10.1371/journal.pmed.1003894>

- Morley, J. and Floridi, L. (2019). The Limits of Empowerment: How to Reframe the Role of mHealth Tools in the Healthcare Ecosystem. *Science and Engineering Ethics*, 26(3), 1159-1183.
- Niranjan, S.J., Martin, M.Y., Fouad, M.N., Vickers, S.M., Wenzel, J.A., Cook, E.D., Konety, B.R. and Durant, R.W. (2020). Bias and stereotyping among research and clinical professionals: Perspectives on minority recruitment for oncology clinical trials. *Cancer*, 126: 1958-1968. <https://doi.org/10.1002/cncr.32755>.
- Oakley, A. (1981). Interviewing women: a contradiction in terms. In: H. Roberts, ed., *Doing Feminist Research*. London: Routledge, pp.30-61.
- Ouschan-Macrae, R., Sweeney, J., Johnson, L. (2006). CusWiller Empowerment and Relationship Outcomes in Healthcare Consultations. *European Journal of Marketing*, 40 (9-10), 1068-1086.
- Patel, M., Chang, S. and Volpp, K. (2019). Improving Health Care by Gamifying It. *Harvard Business Review*, [online] Available at: <https://hbr.org/2019/05/improving-health-care-by-gamifying-it>. [Accessed 01 June 2022].
- Pulvirenti, M., McMillan, J., Lawn, S. (2011). Empowerment, patient centred care and self-management. *Health Expectations*, 17, 303-310.
- Renjith, V., Yesodharan, R., Noronha, J. A., Ladd, E., & George, A. (2021). Qualitative methods in health care research. *International Journal of Preventive Medicine*, 12(1). https://doi.org/10.4103/ijpvm.IJPVM_321_19
- Rock Health (2020). Diversity in digital health: 2020 annual report. <https://rockhealth.com/reports/diversity-in-digital-health-2020-annual-report/> (accessed Jan 07, 2022).
- Saini, A. (2019). Superior: the return of race science. Beacon Press.
- Sarantakos, S. (2005). Social research. NY: Palgrave Macmillian.
- Sharma, M. (2019). Applying feminist theory to medical education. *The Lancet*, 393, 570–78.
- Sharon, T. (2016). Self-Tracking for Health and the Quantified Self: Re-Articulating Autonomy, Solidarity, and Authenticity in an Age of Personalized Healthcare. *Philosophy & Technology*, 30(1), 93-121.
- Shaw, J., Baker, M. (2004). “Expert patient”—dream or nightmare? *BMJ*, 328(7442), 723-724.
- Smith, L. T. (1999). Decolonizing Methodologies: Research and Indigenous Peoples. Zed Books: London.
- Sokka, T. (2003). Work disability in early rheumatoid arthritis. *Clin Exp Rheumatol.*, 21: S71-S74.
- Stolz-Fink, M., Ma, X., Traue, H. (2015). Trust in Digital Technology: Reliability and Validity. *Conference paper: International Symposium on Companion Technology*.
- Srivarathan, A. (2021). 'You Are Kind of Like One of Us': Exploring Researcher Positioning in Studying Community-Based Health Promotion Interventions Among Social Housing Residents of Danish, Turkish and Pakistani Origin. *Qualitative Health Research*. <https://doi.org/Artn10497323211067523>
- Stanley, L., (1996). The Mother of Invention: Necessity, Writing and Representation. *Feminism & Psychology*, 6(1), pp.45-51.

- Stanley, L. and Wise, S. (1993). *Breaking Out Again: Feminist Ontology and Epistemology*. 2nd ed. London: Routledge.
- Swan, M. (2009). Emerging Patient-Driven Health Care Models: An Examination of Health Social Networks, Consumer Personalized Medicine and Quantified Self-Tracking. *International Journal of Environmental Research and Public Health*, 6(2), 492-525.
- Varma, T. Jones, C.P., Oladele, C. Miller, J. (2022) Diversity in clinical research: public health and social justice imperatives. *Journal of Medical Ethics*, 10.1136/medethics-2021-108068, (medethics-2021-108068).
- Van Dijck, J. (2014). Datafication, dataism and dataveillance: Big Data between scientific paradigm and ideology. *Surveillance & Society*, 12(2), 197-208.
- Winker, D. and Degele, N. (2011). Intersectionality as multi-level analysis: Dealing with social inequality. *European Journal of Women's Studies*, 18(1), 51-66.
- Woodcock, J. and Johnson, M. (2017). Gamification: What it is, and how to fight it. *The Sociological Review*, 66(3), pp.542-558.
- Zampino, L. (2019). Self-tracking Technologies and the Menstrual Cycle: Embodiment and Engagement with Lay and Expert Knowledge. *Italian Journal of Science & Technology Studies*, 10(2), pp.31-52.