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Muscle as medicine: an autoethnographic study of coping with polycystic ovarian syndrome through strength training

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ABSTRACT
How can women who are coping with a polycystic ovarian syndrome (PCOS) diagnosis and subsequent illness management overcome the emotional tensions that arise? I propose that through strength training, a stereotypically masculine activity, women can re-gain a sense of femininity that is lost while living with the symptoms of this condition. Framing strength training as medicine can give women with PCOS a sense of control and empowerment while dealing with a chronic condition that often leaves women feeling powerless, as there is neither cure nor explicit cause. In this article, I use autoethnography to describe the lived experience of the initial diagnosis, illness disclosure to others, navigation of health information and self-management of the condition, while unpacking the feelings of guilt, self-pity, anger and lack of control that arise. This study adds a sociological perspective to the predominantly medical and psychologically focused literature on PCOS, giving an in-depth voice to this condition. While framing ‘muscle as medicine’ can have positive implications, I argue that that an ‘exercise is medicine’ framework can be overly agentic and lose sight of opportunity structures and larger social forces that shape a person’s ability to metaphorically self-medicate in this way.

Diagnosing ‘the Trifecta’: a mixed bag of emotions

I laid on the examination table at the endocrinologist’s office, unclothed from the waist down, feet placed in the stirrups. A paper sheet was draped over my thighs. They tremored from nerves and discomfort while the doctor spread bright blue jelly on the ultrasound apparatus. A timid medical student watched on as the doctor did this for what was probably the 20th time that day. She could likely do it with her eyes closed.

‘It might feel a little cold,’ she said with a smile.

I was too distracted to notice whatever coolness there might have been as the long cylindrical object investigated whether or not I had any cysts on my ovaries. My head cocked back awkwardly as my eyes were glued to the ultrasound screen over my right shoulder.

‘I am not a physician, but I knew what I was looking at. My ovaries were immediately recognizable – like the diagrams I had once seen in high school health class, and the images Dr. Google showed me whenever I searched for an explanation for my irregular menstrual cycles. My ovaries looked as though they were covered in pearls – like someone spilled a bag of them all over my ovaries, leaving no surface untouched.

‘I can’t even count how many there are,’ the doctor said, seemingly unalarmed by the sight. I was wide-eyed.

This was the third doctor I had seen in three weeks. A primary care physician suspected I had polycystic ovarian syndrome (PCOS) when I told her my menstrual cycles were unpredictable. I have had unexplained
pelvic pain for as long as I can remember, but thought it was a ‘normal’ part of womanhood, or somehow related to poor digestion or undiagnosed lactose intolerance. Persistent acne made me feel half my age. Pesky, course chin hairs continued to re-emerge despite my best efforts to pluck and shave with diligence. I cannot count how many times I have thought that I removed all of the hairs before heading out of the house, but then after I get in the car, put it in reverse, and look at the magnified close-up of my chin in the rearview mirror I quickly realize that I need to go back inside and tweeze more closely. On a couple of occasions, I have to go back inside twice to re-shave or attempt to better camouflage a blackhead with another layer of foundation. The thought of someone noticing my facial hair or mindlessly staring at my acne scars dismayed me, especially as I was teaching a group of undergraduate students whose skin often looked more distanced from puberty than mine.

The primary care physician referred me to an OB-GYN, who also believed I had PCOS but wanted to do a few blood tests to be sure. She was youthful, bubbly, and wore a plastered-on toothy grin as she talked to me about my potential PCOS diagnosis as if I was anticipating an upcoming trip to Disney World. Sure enough, my blood tests revealed that my testosterone levels were elevated and my Hemoglobin A1C levels indicated that I was as close as it gets to prediabetes. My score was 5.6. The lowest rung of prediabetes is 5.7. After getting the blood test results, she referred me to the endocrinologist.

This ultrasound would solidify my diagnosis. Seeing the cysts on my ovaries sealed the deal.

‘You have the trifecta!’ the doctor said, with a laugh.

I laughed nervously, trying to crack a smile.

For some, having a diagnosis can provide comfort. A parent whose child chronically struggles with unexplained inattentiveness might find relief in an ADHD diagnosis – an official legitimation and medicalized recognition of a person’s unidentified adversity that can be alleviated with pharmaceutical management. A diagnosis provides a label for what is wrong with you, suddenly making your symptoms a ‘real’ concern when describing them to others.

For me, ‘the trifecta’ opened a mixed bag of emotions. The tension between taking a nerve-ridden, labored inhale and a relieved yet numbed exhale that came with my diagnosis is difficult to describe. The verdict over my symptoms made more real that I would have difficulty conceiving, be at higher risk of diabetes, have a lifetime of weight management issues, and struggle with years of unruly acne and facial hair. I felt bitter that most of my peers could have babies on accident, or better yet, they could plan – and control – when they became parents. My years of paranoia over avoiding becoming pregnant were apparently wasted energy. Most of my friends can wash their smooth faces without thinking about the pimple days of the past, but every evening when I wipe the layers of honey-hued powder and concealer off of my face, revealing redness, scarring, whiteheads, and stubble, I’m reminded of my permanent reality.

After a few minutes of loathing, I unearthed an opposing, glass half-full voice in my head saying, ‘At least it’s not cancer – you are not dying.’ I was thankful to know what was going on with me. It was not fatal, it was not imminently dangerous, and it was not an unknown condition they had never seen before. ‘Wearing makeup, plucking, and fertility treatments are not the end of the world,’ I thought. I was angry at my body and sad at this diagnosis, but grateful that I was not one of the many people at the doctor’s office each day who receive much worse prognoses. The strain of these two conflicting feelings was overwhelming.

‘Besides the cysts, does everything else look okay?’ I tried to sound as relaxed as possible. I hid my sweaty palms.

‘Oh yeah, everything looks great,’ the doctor said, snapping the gloves off of her hands and quickly throwing them in the trash.

‘You can get dressed and head back to my office so we can chat.’

She smiled and quickly left the room.

**Polycystic ovarian syndrome**

Stein and Leventhal (1935) first wrote about PCOS in their publication titled, ‘Amenorrhea associated with bilateral polycystic ovaries’ (Ehrmann 2005, Azziz and Adashi 2016). It is now one of the most common hormonal disorders ailing women (Ehrmann 2005), affecting approximately 5 million women
– about 5% of those of reproductive age in the United States (Knochenhauer et al. 1998, Asuncion et al. 2000). Medical professionals speculate that there are even more women who have it but have not been formally diagnosed (Dowdy 2011).

PCOS is one of the most common causes of anovulatory infertility (Azziz et al. 2004). Oftentimes, women live with the condition unknowingly for years thinking that their symptoms are normal. Many only receive a diagnosis once they are having difficulty with conception even though symptoms often start around the initial onset of menstruation (Ehrmann 2005).

The exact aetiology of PCOS is unknown, but genetic history is known to play a role. Whether or not a relative has the condition is often asked of women who present symptoms to their doctors (Goodarzi et al. 2011). Lifestyle factors are known to be a factor as well. PCOS is considered a ‘lifestyle disease in which genetic predispositions may in fact be activated by lifestyle factors’ (Pathak and Nichter 2015, p. 21). Recent research conducted on mice points to the possibility that neurological conditions may even contribute to the development of PCOS (Caldwell et al. 2017).

PCOS is known to be difficult to diagnose because there is not one specific diagnostic examination that can be conducted to determine whether or not a woman has this condition. Polycystic-appearing ovaries (PAO) alone cannot constitute a diagnosis, as ‘multiple insults need to come into play after puberty for women with PAO to develop PCOS’ (Carmina and Lobo 1999, p. 1897). These ‘insults’ can include insulin resistance, obesity and stress (Carmina and Lobo 1999).

The NIH (2012) highlights three sets of diagnostic criteria that are often referenced. The NIH Criteria from 1990 calls for a woman to have both chronic anovulation and clinical and/or biochemical signs of hyperandrogenism. In 2003, the Rotterdam Criteria required a patient to fulfil two of the following three criteria for a diagnosis: (1) oligo- and/or anovulation; (2) clinical and/or biochemical signs of hyperandrogenism; and (3) polycystic ovaries. Similarly, the Androgen Excess and PCOS Society’s 2006 criteria prescribed that a woman have clinical and/or biochemical signs of hyperandrogenism and ovarian dysfunction in the form of irregular menstruation and/or polycystic ovarian morphology. While these symptoms are being assessed, medical practitioners – no matter what set of criteria is being applied – must simultaneously eliminate the possibility that a woman has another disorder causing hormonal irregularities such as hyperprolactinemia, nonclassic congenital adrenal hyperplasia, Cushing’s syndrome, androgen-secreting neoplasm or acromegaly (Ehrmann 2005). The lack of consensus over the diagnostic criteria is ‘confusing and delays progress in understanding the syndrome’ and ‘hinders the ability of clinicians to partner with women to address and manage the health issues that concern them’ (NIH 2012, p. 2).

Phenotypically, there are wide ranges in the severity of physical symptoms, further complicating the ability to diagnose and manage PCOS. Not everyone with PCOS has acne, facial hair and ovarian cysts. Among those that do, they can exist at varying degrees. This heterogeneity further complicates the diagnosis process, as not everyone with PCOS may present all of the symptoms (Yen 1980).

Despite the condition’s diversity, there are common issues that many of those with PCOS must deal with: namely, difficulties managing body weight and problematic blood sugar levels. Women with this condition are at a substantially higher risk of developing metabolic and cardiovascular abnormalities. Studies have estimated that 30–75% of women with PCOS have obesity (Ehrmann 2005), while a somewhat substantial minority of patients have what is considered a healthy BMI (Franks 1995). Additionally, PCOS is associated with an elevated risk of becoming diabetic (Talbott et al. 2007). As such, 30–40% of women with PCOS have impaired glucose intolerance, with about 10% developing diabetes by age 40 (Ehrmann 2005). Research has found that losing as little as 10% of one’s bodyweight is associated with decreased male hormones, more regulated menses and a slowed progression of diabetes (Meisler 2002). Therefore, those that have PCOS are told that adopting particular health lifestyles are the best ways to manage. In particular, eating a diet low in carbohydrates and focusing on strength training (in addition to blood sugar medication, for patients with insulin resistance) are often recommended in order to balance sugar and hormone levels.

Living with issues of body weight, insulin resistance and the undesirable phenotypic features of PCOS can affect women’s psychosocial well-being (Schmid et al. 2004, Weiner et al. 2004, McCook et
al. 2005). For example, women living with PCOS have a higher prevalence of depressive symptoms compared to those without the disease (Cipkala-Gaffin et al. 2012). Women with unwanted and/or excessive hair growth, obesity, amenorrhea, acne and infertility have a significant anxiety related to their inability to conform to dominant culture’s notions of an appropriately ‘feminine’ appearance and bodily behaviour (Kitzinger and Willmott 2002). This is compounded by the normative pressure on women to take advantage of their time-sensitive ‘reproductive capital’ – fecundity that depreciates with age (Low 2014) – as PCOS typically has an adverse effect on fertility. Even though PCOS is linked to significant psychiatric distress in only a relatively small proportion of those with the disease, the tie between PCOS and emotional distress, decreased sexual self-worth and diminished sexual satisfaction is apparent (Elsenbruch et al. 2006).

In sum, PCOS is a varied condition with no universal treatment plan, no typical illness experience and of utmost significance, no cure. This may be in part why few social scientists have taken on the task of giving voice to the PCOS illness experience – it is largely ungeneralisable and its sufferers stay silenced due to its difficult, embarrassing and stigmatising nature.

**Disclosing my condition: dismissal, reassurance and tears**

After the diagnosis sunk in for a week, I decided I would tell friends and family about my diagnosis if it seemed to fit into conversation. I was at a restaurant for lunch with a friend, and as we were catching up and eating our salads I mentioned casually that I was cutting back on carbohydrates because I have PCOS. Situations surrounding food seem to be a fitting place to slip this into conversation. I gave a very minimal explanation: ‘I have this condition where I have cysts on my ovaries and it is much more likely I will get diabetes.’

‘Okay,’ my friend responded. ‘Can I have your bread then?’ she asked with a laugh, eyeing the warm chunk of baguette next to my bowl.

‘Sure,’ I responded.

The conversation continued as usual. It felt as though I had just told her that I am nearsighted or I have a bothersome hangnail. It was nearly a non-issue. ‘Maybe my anxiety over this condition was overblown,’ I thought. After all, this particular friend survived childhood cancer a couple of decades ago. Who was I to make a big deal about not being able to eat bread?

Some of my closest friends asked more questions about PCOS and its implications, but no one seemed particularly stunned when I disclosed my condition. Their laidback replies were reassuring and allowed for a momentary escape from any self-pity I was feeling.

‘My friend’s sister has that,’ one friend told me as we chatted over our email’s instant messenger. ‘She got treatment and had two babies. It’s really treatable.’ Maybe she was right. I felt a little better. When a rush of anxiety would wash over me, thinking about my friends’ sentiments provided moments of calm.

Two weeks after my diagnosis, I was on the phone with my mother. We talk every week for at least an hour or two, and tell each other nearly everything. I debated incessantly about whether or not to tell her, but whenever I thought about talking to her about it my palms would sweat. Between her stressful job and aging parents, my condition didn’t need to be added to her plate. I wasn’t dying.

My plan was to wait until I am pregnant someday in the future, then after I give birth I could mention casually, ‘It is particularly amazing that this child is here because we had to undergo infertility treatment – I have PCOS! But look, it doesn’t matter now, because we have this beautiful baby!’

This fantasy faded fast. The thought of waiting that long made my hands sweat more profusely. It was eating away at me. I couldn’t wait that long. Despite my friends’ relaxed responses to my diagnosis, I still teetered toward feeling bad for myself and my uncertain future more often than not.

‘So, I found out I have PCOS. It shouldn’t be a big deal, except that if I want to have children in the future I’ll have to take a medication for infertility and it’s more likely I will get diabetes,’ I said to my mom over the phone, in a tone as casual as I could muster. I didn’t want her to worry. ‘This finally explains why I have always gotten those stupid hairs on my chin!’
‘Oh, I know someone whose daughter had PCOS. She took a medication and eventually had a baby,’ she responded, very matter of fact. ‘Did I tell you what my boss said this week? It was such a crazy week ……’ She continued to talk after what was treated like a small blip in the conversation.

I was glad she was not worried, but I wanted her to at least feign concern. I thought about this daily—maybe even hourly—but everyone I was telling seemed to think about it for two passing seconds. As selfish as it sounds, I wanted a pity party. I silently cried while my mother flipped through topics as easily as the television channels.

After we hung up, I sent her a text message. I told her I was surprised at her blasé reaction to my diagnosis. My phone immediately rang.

‘I changed the topic because I didn’t want to cry, and I knew if I cried that would make you cry,’ my mother said quietly. ‘Is it okay if I cry?’

‘Yes,’ I said.

**PCOS: lived experiences**

Few researchers have explored PCOS through a sociological lens, understanding personal experience as being shaped and understood within larger social structures. In addition, much of the research exploring the lived experiences of those with PCOS is outdated and problematic, with several studies connecting PCOS with psychopathologies and ‘deviant sexuality’ (Kitzinger and Willmott 2002, p. 350), while being limited to a clinical settings (e.g. Snyder 2006, Percy et al. 2009, Crete and Adamshick 2011). Despite the relatively widespread nature of PCOS, prior to 2002 there was ‘no feminist work addressing the experiences of women with PCOS’ (Kitzinger and Willmott 2002, p. 350), and narrative studies on the condition are very limited even since.

However, several studies have been conducted in recent years that have begun to explore the lived experiences of women with PCOS. Through interviews, Snyder (2006) found that her participants wanted to be ‘normal’, attempted to achieve ‘femininity’, found themselves searching for answers and struggled to let go of guilt. Likewise, Crete and Adamshick (2011) reported that women managing PCOS were frustrated, confused, searched for answers and grappled with the desire to gain control over their health and bodies. Others have highlighted the importance of screening those with PCOS for depressive disorders, noting that psychosocial support should be emphasised given the changes that women go through when living with this condition (Weiss and Bulmer 2011, Williams et al. 2015). These studies have been instrumental in beginning to give voice to women who have been diagnosed with PCOS. However, they are often positivistic in nature as they attempt to quantify qualitative responses by highlighting salient themes with short quotes as evidence. Decontextualised data make it difficult to get a full picture of what women with PCOS are going through as they move through their daily lives.

In their interviews with women living with PCOS, Kitzinger and Willmott (2002) note that they were struck by the fact that 17 of their 30 participants had never met another woman living with PCOS, to their knowledge. This illustrates the hidden nature of this condition. The researchers highlight the common experience of feeling like a ‘freak’ because of ‘failure to conform to the norms of “proper woman-hood or femininity” due to the symptoms commonly experienced by those with PCOS, in particular, menstrual irregularity, infertility and facial hair (Kitzinger and Willmott 2002, p. 352). Regarding her struggles with infertility, one woman in the study said that her ‘whole purpose of being a woman was gone’ (Kitzinger and Willmott 2002, p. 357). In short, this study highlights how PCOS can make it challenging to see oneself as a ‘normal woman’, and the hushed nature of the condition can cause those living with it to feel isolated, different, alone and unrelatable to peers.

This article builds on this work about the experience of having this condition, giving voice to the self-management of PCOS and the emotion work involved with grappling with contradictory feelings. I take a long-armed approach by including the experience of diagnosis, disclosing the condition to others, interacting with my doctor and navigating the depths of health information available to those with PCOS. To better understand the coping phase of PCOS, we need to understand the preceding experiences women must deal with and how they can potentially shape the processes of self-management.
Autoethnography as a means for conveying the experience of coping with PCOS

I chose to approach this topic through the lens of personal experience, using autoethnography to critically examine my own experience and situate it within a broader sociocultural context in order to ‘fuse the personal and societal’ (Sparkes 1996, p. 463). As such, I am also ‘connecting the personal to cultural’ (Ettorre 2005, p. 535). Ellis et al. (2011, p. 273) write that it is an ‘approach to research and writing that seeks to describe and systematically analyse (graphy) personal experience (auto) in order to understand cultural experience (ethno): Sociologists who engage in autoethnography ‘zoom backward and forward, inward and outward’ (Ellis and Bochner 2000, p. 739). Of studies using narrative inquiry, Bochner and Ellis (2003, p. 509) write that they should ‘be stories that create the effect of reality, showing characters embedded in the complexities of lived moments of struggle, resisting the incoherence, trying to preserve or restore the continuity and coherence of life’s unity in the face of unexpected blows of fate that call one’s meanings and values into question.’ There have been many researchers before me who have paved the way for scholarly reflection on personal illness and sports-related health experiences (e.g. Zola 1982, Charmaz 1991, Sparkes 1996, Rier 2000, Allen-Collinson and Hockey 2001, Collinson 2005, Dashper 2013, Frank 2013). It is on the shoulders of this scholarship that the present study derives its inspiration.

Jones et al. (2013, p. 32) write that autoethnography has five purposes that make it compelling as scholarly means of understanding: (1) it disrupts the norms of positivistic research practice, shifting the way that we represent those we study; (2) it operates from insider knowledge; (3) it manoeuvres through difficult emotions such as pain and uncertainty; (4) it gives voice to silenced people and areas of inquiry; and (5) it makes research accessible. Given this criteria, autoethnography is a complementary contribution to our current understandings of PCOS. Unlike previous work that presents a dichotomy between ‘the researcher’ and ‘the researched,’ this type of research engages in a ‘blurring of the object/subject dichotomy’ that ‘comes from the scholar gazing at the self gazing at others’ (Erdmans 2007, p. 9). Erdmans (2007, p. 12) writes that central to narrative scholarship ‘is the mushing together of subject/object and self/society distinctions – the observer is an insider; the self is a social form.’ Further, this type of research highlights a ‘heightened self-reflexivity in ethnographic research’ (Anderson 2006, p. 373).

Autoethnography acknowledges that silenced emotion and objectivity are not necessary – or possible – in many (if any) forms of social research. On the contrary, autoethnography embraces that bringing feelings, prior knowledge and opinions into the forefront can be beneficial for better understanding the complexities of the human experience. Autoethnography is a mode of knowing and way of being, and good autoethnography both ‘soothes and causes discomfort’ for both the narrator and the reader (Sparkes 2013, p. 512). My aim of giving voice to women with PCOS and providing in-depth description of the emotions involved with diagnosis, disclosure and coping with the condition make autoethnography an appropriate enterprise for better understanding PCOS.

Further, autoethnography’s aims – to provide thick description and evoke emotion – lend themselves to social scientists’ study of the illness experience. Sociologists have highlighted the ‘progressive separation of the medical model of disease from lay experience of disease’ (Bury 2001, p. 266), and the need for this separation to be diminished in order to better serve individuals’ health needs. The decline of infectious disease and rise of conditions caused by health lifestyles lends itself to grasping patients’ experiential knowledge. Bury (2001, p. 266) writes that ‘the everyday management of chronic illnesses to proceed, their heterogeneous character (in terms of the multifarious ways disabling symptoms interact with the “life worlds” of home and the work place) become the focus of both lay and professional concerns’. Given the commonality, diversity and unspoken nature of PCOS, the number of narratives left untold are unknown, but are undoubtedly numerous. The relative silence of PCOS in popular culture and social science alike needs to be eradicated if the goal of bridging laypeople’s experiences and practitioners concerns, as well as understanding women with PCOS’ experiences as being contextualised within a larger social context, is to be achieved.

The phases of my PCOS narrative and my introspections of how my experiences are shaped by gender roles, gendered expectations, social relationships and the institution of medicine are interwoven with
relevant literature in order to contextualise my experiences within a social context and previous research. Although each person's experience with illness is different, particularly for those with medical conditions that are heterogeneous in nature, we can find commonality in re-occurring themes and emotions. As such, this study is not generalisable to a population. I do not represent everyone with PCOS. A limitation of this type of work is that my experiences are not meant to typify those of other populations (e.g. low-income women, older women, those with little experience with exercise) or to those experiencing this condition in the past or in the future. It is important to understand that my experiences should be understood within the specific experiential context of a middle-class woman in her late 20s who was recently diagnosed, although I do not claim that my experiences epitomise women with PCOS of similar social standing either. Undoubtedly, if I waited a few years to write this, my autoethnography would likely read differently. Likewise, as new research is emerging on the roots of this condition, someone who is newly diagnosed with PCOS in 20 years may also have a very different experience.

Like Tulle's (2017, p. 175) recent article in which she uses narrative to shed light on her experiences as a hillwaker, 'I am aware of the personal risk I am taking in making aspects of my personal life public', but 'the impetus was not a narcissistic undertaking per se but a critical examination'. I began to take notes on my experiences as soon as I was diagnosed, and started writing this article nine days later. As I conducted literature reviews and personal research, I quickly learned that the need for more voices of PCOS in academic literature was urgent. I continually took field notes and wrote my narrative throughout the three months post-diagnosis while changing my eating habits and engaging in strength-building exercises at the gym about six days per week.

While personal in nature, my hope is that the narrative presented can give a voice to an experience of PCOS in a way that is relatable to others with the condition, as well as those without.

Treatment: re-framing exercise, a new phase of life

‘Don’t just sit on the elliptical,’ the doctor instructed as we sat in her office after my ultrasound. ‘You need to do strength training. Try CrossFit or bootcamp classes.’

She typed it into my chart as she told me, glancing back and forth between me across the desk and her computer screen beside her.

‘You could try the South Beach Diet, too. Low carb,’ she said passively as she continued to type.

My BMI was a nudge too high for the medical establishment’s liking. I would not describe myself as ‘fat’ at 5’6, 155 pounds, but I was certainly not petite. My arms are fairly toned, but I inherited the thick Smith thighs – re-enforced from years of playing soccer and basketball. She said I should try to lose a few pounds.

During the small talk portion at the beginning of my appointment, I had mentioned how I am writing my dissertation about black women who run and their exercise behaviours.

‘You should take after them,’ she said with a laugh.

My heart sank. I felt embarrassed. Do I look like I don’t exercise?

In fact, I AM a black woman who runs. I did not bother to tell her that I was a pescatarian, a former college basketball player, and I have run six half marathons. I debated bringing it up, but my frustration silenced me and I was sure she hears patients spew what she believes to be excuses all day. I smiled to hide my emotions and nodded in acknowledgement.

How could I – a 20-something former college athlete who works out regularly and eats relatively healthily – find herself sitting in the doctor’s chair being told to exercise? I read regularly about black women’s poor health outcomes, but never thought I would be the face of a condition that is viewed in part as resulting from an unfit lifestyle. Dominant culture tells us that what you put in your mouth and how long you sit each day are under an individual’s jurisdiction. In today’s health-conscious world, overweight people are made to believe that their bodily state is due to personal shortcomings, a personality flaw, a lack of care, or laziness. As a sociologist, I know that it is far more complex and structural than being a result of an individual’s faults, but I did not want to be thought of that way by loved ones and the general public, especially because of my athletic and academic background. My doctor’s comments, however innocuous, did not sit well with me.
The doctor continued, telling me that she puts most of her patients on Metformin, an anti-diabetic medication, to manage their blood sugar levels, but mine was only borderline problematic. I told her I wanted to try and take care of this myself.

‘I exercise now, but I’m sure I could do more. I’ll eat better too,’ I said shyly. I was a little nervous, knowing that I already worked out 4-5 days per week, never ate fast food, and was fairly conscious of my calorie intake. But being an athlete most of my life, I believed you can always work harder, eat better, and achieve more. I used to spend hours at the gym doing cardio, lifting weights, and shooting baskets. For as long as I can remember, from childhood through college, I wanted to be one of the best players on the basketball team. Nowadays, I still worked out, ran, and used the elliptical machine, but my lifting was less consistent. Oftentimes, I just went through the motions with my workouts. I didn’t really have a specific goal besides ‘don’t get fat.’ I spent much of my early 20s obsessed with calorie counting and fearing the scale. After college, my weight fluctuated with the time-binds of graduate school, the stresses of new jobs, and newlywed euphoria-induced overeating. Still, whenever I worked out, exercise was framed as something that had to be done to fend off fat and burn away calories.

This conversation with the doctor was a turning point that I cannot imagine I will ever forget. It forced me to re-frame how I thought of exercise. It was no longer to burn calories, to ‘look good,’ or to be a better athlete. Now, it truly was a form of medicine – a way to treat PCOS and prevent other chronic issues from stemming from its roots.

Mentally, I entered a new phase of life.

I took the doctor’s recommendation to lose weight and lift weights as a challenge – like training for a marathon or working to earn a starting spot on the basketball court. Except this time instead of lowering my mile time or improving my 3-point shooting percentage, I wanted to lower my A1C. I wanted to show the doctor that I wasn’t just another patient she would bet on leaving the office and never entering a gym.

My appointment transitioned into the wrap-up phase.

‘I can continue seeing you if you want to chat about PCOS, but if you encounter difficulties conceiving I won’t be able to help much further. It isn’t covered by your insurance – or most insurances for that matter,’ she said hesitantly. I sensed pity in her voice as she undoubtedly knew I would have issues. We were divided by a desk, but in that moment we could both connect over the helplessness we felt. Both she and I were constrained by the capitalist, machine-like medical institution.

As she spoke, the weight of burden that had been lifted as I received a diagnosis quickly re-emerged as my task list – workout intensely, eat low-carb, don’t get diabetes, don’t gain weight – a list of lifestyle behaviours and a new mindset that might not even be effective in curbing symptoms – got longer.

‘My husband has it so easy,’ I thought.

My health destiny really was up to me, and perhaps, a bit of luck. I internalized everything the sociologist in me scrutinized.

The seemingly invincible days of routine, uneventful doctor’s visits of my youth were over. This must be what it feels like to be a ‘real adult,’ I thought. Earlier obsessions with losing weight to look skinny in my wedding dress or toned in a bikini sunk below the surface. It was now about preventing myself from getting diabetes, curbing acne and facial hair, and keeping the hope alive that I could eventually conceive a child.

As I left the doctor’s office I was simultaneously frustrated, annoyed, and determined.

‘I’ll prove her wrong!’ I said to my husband on the phone, walking briskly through the parking lot. It was raining and I stomped through the puddles.

‘Am I fat? Do I really not look like I exercise?’ I asked him frantically. Suddenly I felt like I looked much larger than I realized.

He sighed. ‘No, of course not. Doctors tell everyone this stuff. She tells everyone to lift weights, honey – don’t take it personally,’ he responded. He’s a nurse, so I tried to trust him but I did take it personally.

Shortly after we got home, I got on Google. After all, I am a researcher. I could not allow myself to become another statistic. I scoured the Internet. I conjured up as many search terms as I could as to not miss a good resource, or a key piece of information.
I was buried in URLs. My inability to read through the vast information available, sorting through that which was legitimate and that which was not, made me feel entirely out of control – the opposite of how I wanted to feel as I attempted to harness knowledge as a source of power. Isn’t having all of these advanced degrees supposed to allow me to exercise more agency over my life?

But as I kept digging, I noticed patterns – the recommendations were much of the same. Eat a ketogenic, low-carb diet. Eat whole foods rather than processed ones. Eat fruits and veggies, but not too much fruit so as to avoid sugar. Avoid gluten and dairy.

It wasn’t all about food though. One thing kept emerging over and over again: Exercise.

Specifically, high-intensity interval training and weight training. I perused a few blogs about women who used to run marathons but quit when they were diagnosed with PCOS.

I Googled ‘PCOS Personal Trainer’ on a whim. Sure enough, one popped up. She has the condition herself and dedicates her life to creating high-intensity home workout plans for women working to manage their condition. As I read the comments section on her website, filled with notes from women who have been helped by her blog posts, videos, and workouts – all whom have struggled with the same symptoms I have – I felt much less alone.

After a few hours, I was simultaneously relieved and completely overwhelmed. Having more information and a plan of action gave me a sense of control, but lingering doubts made me wonder if it was all a façade. After all, there are dozens of online discussion boards filled with women with PCOS who are desperate for answers, struggling to lose weight, improve skin, and have a child after many years of distress. They all had access to the same information on Google that I did, yet continued to have problems.

Questions poured into my head. What if I eat a low-carb diet, strength train, lose 20 pounds, and still get diabetes? After all, my mom is pre-diabetic and three of my grandparents have diabetes. Why can the other women in my family so easily conceive, but because I do not ovulate, I inevitably will not? Will I ever be able to get my acne to a minimal level so it can be completely covered? Will I ever experience life free from the mental and lifestyle constraints of worrying about weight?

I took a deep breath, closed my laptop, put on my workout clothes, and headed to the gym.

**Health lifestyles as a key to PCOS management: a sociological perspective**

Health lifestyles (Cockerham 1995, 2005) are seen as the key to treating PCOS. Medical sociologists describe health lifestyles as ‘pattern[s] of voluntary health behaviour[s] based on choices from options that are available to people according to their life situations’ (Cockerham 1995, p. 90). Those in more privileged social classes are typically the first to gain knowledge of new health risks and because of greater resources are most able to adopt new health strategies and practices (Link and Phelan 2000, Bell 2014). While health lifestyle activities can include having regular check-ups with a physician, they typically refer to those activities outside of the health care delivery system such as diet and exercise, stress management, drug and alcohol use, dental hygiene and sleep regularity (Cockerham et al. 1997).

A growing focus on health lifestyles emerged as a result of the ‘epidemiological transition’, which encompasses ‘the complex change in patterns of health and disease and on the interactions between these patterns and their demographic, economic, and sociologic determinants and consequences’.
In years past, social conditions – living environments, sanitation methods and medical practices – were more conducive to the spread of infectious disease. Now, we have more advanced medical technology, a proliferation of vaccines and antibiotics and improved sanitation practices. Consequently, many of those diseases have faded away – particularly in more developed countries (Olshansky and Ault 1986). Shifts in the most common causes of death from infectious diseases to chronic illness ‘represents a transition from the primacy of material constraints to social constraints as the limiting condition on the quality of human life’ (Wilkinson 1994, p. 61). As such, chronic medical ailments – lifestyle conditions’ such as PCOS – have been on the rise in recent years. As a by-product, the onus on patients to take responsibility for their health is also mounting.

Rather than relying on medical experts, individuals in Western nations are increasingly expected to take responsibility for their own health whenever possible (Glassner 1989). This aligns with the culture of meritocracy and the ‘American Dream’ ideology: everyone has a chance to work hard and achieve success. When infection and disease were among the leading causes of death, it was often attributed to chance and bad luck rather than an individual’s chosen behaviours. However, avoidance of chronic conditions such as diabetes and hypertension is more likely to be characterised as under a person’s control. Popular views of health have transformed from a taken-for-granted state we do not think much about until it wanes, to an achievement that ‘people are supposed to work at to enhance their quality of life’ (Cockerham 2005, p. 51).

PCOS lies in a grey area. It is framed as under a person’s control due to health lifestyle activities, yet there are inherited, genetic, hormonal abnormalities that can play a role (Goodarzi et al. 2011). Either way, PCOS is arguably exacerbated by poor lifestyle choices and manageable with alternative health lifestyles such as limiting carbohydrate intake and intensely exercising.

In 2011, the PCOS Australian Alliance published the first evidence-based guidelines for the management of PCOS (Alliance 2011). These recommendations prescribed exercise as the ‘first-line of therapy’, recommending 150 min of exercise per week, at a minimum, to improve women with PCOS’s clinical outcomes. Of these 150 min, 90 of them are recommended to be of moderate-to-high intensity.

One study found that physical activity was more effective than Metformin in treating insulin resistance (Knowler et al. 2002). High-intensity interval training has been found to improve insulin resistance among those with PCOS (Almenning et al. 2015). One study reported that in women who previously did not ovulate on their own, a three-month aerobic training programme restored regular ovulation for 60% of the women in the study (Vigorito et al. 2007). Overall, exercise studies show improvements in regulating menses in about 50% of women living with PCOS (Thompson et al. 2011).

Weight training in particular is associated with improving insulin resistance and body composition, preserving lean tissue and quickening a person’s metabolic rate while the body is at rest (Thompson et al. 2011). Some researchers believe that women with PCOS should specifically focus on muscle-building, rather than aerobic, cardio-focused physical activities, for curbing symptoms. Cheema et al. (2014, p. 1204) write:

> There is a physiological rationale for prescribing PRT (progressive resistance training) in women with PCOS. Insulin resistance and androgen excess are interrelated features of the disease that contribute to its exacerbation. PRT has consistently been shown to increase insulin sensitivity in patients with T2DM (type 2 diabetes), and given that the underlying features of insulin resistance are similar between these conditions, it can be hypothesized that PRT can improve clinical outcomes in PCOS as well. Four studies incorporating PRT within a lifestyle-based intervention suggest that this modality of training is feasible to prescribe.

Relatively little research exists, however, on the degree of effectiveness in strength training versus aerobic exercise in managing PCOS (Cheema et al. 2014). Nevertheless, the effect that strength training can have on a woman with PCOS’s psychological well-being – and an enhanced feeling of being ‘in control’ while coping with a condition that makes women feel out-of-control of their body’s processes – could be invaluable.

In line with the present emphasis on personal responsibility, holistic medicine and the ‘cult of health’ (Bourdieu 1984), exercise can – and should – be framed as a type of medicine for those living with PCOS, given its role in curbing symptoms and giving people a sense of control over their health trajectories.
Thus, framing exercise routines as a form of medicine is important – particularly for chronic conditions such as PCOS that are not formulaically treated.

**Taking action: balancing PCOS and performance of self**

I walk through the large, open area with weight machines and an array of cardiovascular machines before entering the weight room – the only section of the gym that is not part of its open floor plan. You cannot peer into the weight room from the outside, besides the glimpses you can catch through the doorway. In the main area of the gym, the slew of cardiovascular machines have monitors on them, roughly estimating the number of calories you have burned. It calculates your time, distance, and on some machines, even heart rate. It gives people a sense of control over their workout. You can make yourself feel as though you are burning off that BLT sandwich from lunch. Weight training is different. There are no monitors or built-in trackers. There is no external, electronic accountability. It’s just you, the weights, and your thoughts.

The weight room at my gym is an enclave filled with worn sweat-covered benches, heavy plates, platforms, and free weights ranging from those a small child could use, to those weighing as much as a small child. This space seemingly has everything one could need to build muscle, and many other contraptions that I don’t know how to use. Fluorescent lighting and walls of floor-to-ceiling-freshly-Windexed mirrors leave nowhere to hide. When someone walks into the room, everyone sees. There is little conversation, as everyone is in their own zones.

Throughout the weeks, the clientele stays mostly the same. Depending on the time of day, I can predict who will be there. Typically, there are not many adults with white hair in the weight room. There are also not many people who appear to be novices struggling to adjust or properly handle a machine. Situated in a private gym on a college campus near a major hospital, the weight room is oftentimes filled with men of average-looking strength that I imagine are medical students, law students, and medical professionals seeking to get more ‘ripped.’ Some sip on protein shakes in-between reps. It is almost unspoken that if you enter this territory, you should know what you were doing – or at least perform with the swagger as if you belong. When I navigate the weight room, I rarely smile and I walk from machine to machine with purpose and without hesitation. Even if I am deciding my next routine on-the-fly, I won’t let others know it.

More often than not, I am the only woman among a sea of staring men. I’m never quite sure if their looks are in admiration of my lifting routine; in contempt at taking up space; in judgment that I am not focused on weight loss via cardiovascular calorie-burning; if the gaze is sexual in nature; or if they are platonic, trance-like gazes that are exaggerated by my self-conscious overthinking derived from maneuvering in a gendered space. These thought processes extend before I even get to the gym: Which leggings should I wear? Is today a shorts day? Should I wear my long, basketball shorts? Are they covering my thighs enough? Is my shirt long enough to conceal the curves I don’t want stared at, tight enough as to not look frumpy, but loose enough to be forgiving? Is today a particularly blemishful-make-up-is-necessary-to-leave-the-house-even-though-I-will-sweat-it-off type of day? Is this a good time of the day to workout? Is it late enough to miss the early morning crowd’s intense, routine lifters, but early enough to avoid the post-9 to 5 rush? Compared to the men surrounding me – many of whom look as though they just rolled out of bed – I expend excessive energy thinking about the process and experience of lifting, rather than the lifting itself, and it is not just because I am a sociologist. Somehow it seems that many of the men on the benches beside me, grunting, staring, and mindlessly texting on their phones between sets, have fewer impressions to manage. My incessant internal questioning was particularly pronounced during the first couple of weeks that I regularly frequented the weight room.

When there are other women in the weight room, I do not perceive that they all endure the same male gaze. Of the staring at other women that I observe men engaging in, their sexual nature is easier for me to perceive. A lot of times, the men are staring at women’s chests or rears, rather than observing the exercises the women are pursuing as a whole. More often than not, the women beside me are lifting single-digit free weights that require minimal effort to curl. They blend in via their conformity with gendered norms for gym behaviour, but with that conformity I cannot help but wonder if they sacrifice their ability to lose themselves in the groove of a workout, attain defined muscles, and the possibility of transforming their bodies, all for the
sake of maintaining a feminine performance. As I walk through the cardio area to get to the weight room, I often wonder how empowered the women on the elliptical machines feel as they try to wither their bodies away rather than build them up. When I sense these judgments are entering my thoughts, I try to suspend overgeneralizations. Anyone who is at the gym should be applauded. Not everyone finds the weight room to be an accessible or comfortable subculture. But I can't help but think about the years I spent obsessed with hitting a calorie-burn goal each time I was at the gym. These goals were out of fear, rather than derived from the desire to feel power over my body. Then again, was I not partially driven by the fear that I may never become a mother if I don’t get a grip of my body and literally shape it?

Initially when I worked out, I was constantly thinking about my condition. I heard my doctor in my head. I made myself view my workouts like brushing my teeth. I would not skip brushing my teeth for a day because I am tired. I do not want to get cavities. Why would I skip a workout and risk getting diabetes? If the medical institution doesn’t know how to fix me – nor would it pay for it even if it could – than it was up to me to self-medicate. I didn’t abandon running and using the elliptical, but it became a short, high-intensity appetizer for my strength-focused main course rather than a calorie-burning trudge through time. It’s 20-minutes of intervals that leave me drenched in sweat, rather than 75 minutes of leisurely gliding on the elliptical.

When I lift, I do not lift small weights. I try to lift the heaviest weights I can, even if it comes at the expense of pleasant facial expressions and dainty feminine movements. When I lift, sweat drips down my face. Sometimes I breathe heavily. Impression management flies out of the window as my mind is thinking of nothing but the rep number I am on and the song pouring through my headphones.

After lifting for a couple of weeks, I could sense the changes in myself. I could see changes physically with my triceps becoming more chiseled, my legs tighter, and glimpses of abdominal muscles. My skin got a little bit clearer.

After several months of my new lifestyle, I had lost 10 pounds. Of course I will not know whether or not my nutrition, my lifting, or both were the primary contributors to these changes, but I believe that strength training made a difference—especially in the less tangible ways. I still thought of my condition while I worked out, but only when I felt fatigued or wanted to quit and go home early and it emerged as a source of motivation.

My head was clearer. The thoughts that muddied my head since my diagnosis were muted more often. I felt more like a woman on a mission rather than a woman who has fallen victim to an inevitable life of relatively minor (albeit frustrating) misfortune. It is in these moments of strength training-induced adrenaline that I lose sight of my PCOS, consumed by a lifter’s high. For that 30–60 minutes that I am lifting weights, I feel transported from the confines of PCOS and societal norms as I get wrapped up in my own little world of self-improvement, self-defined goals, and the empowerment of exercising agency over my body – pushing it to new limits every time I enter the gym.

Women in the weight room

Women in the weight room must negotiate feminine identity within the masculine environment of the weight room and gendered expectations about muscularity. For women with PCOS, there is a particular tension – a contradiction – that emerges as they surround themselves with men in the weight room while engaging in a stereotypically masculine activity. With the goal of putting on muscle, a masculinised ideal, women with PCOS have the goal of feeling more feminine via minimisation of facial hair, acne, bodyweight and regained ovulation. While lifting heavy weights – a masculine act – women simultaneously perform femininity through their clothing, hairstyles and conduct.

Muscularity is generally seen as inappropriate for women (Choi 2000). As such, women who lift weights in pursuit of muscularity have been labelled ‘gender outlaws,’ ‘a group who are stigmatised … because they disregard so flagrantly people’s sense of what is aesthetically, kinaesthetically, and phenomenologically acceptable within the gendered social order’ (Shilling and Bunsell 2009, p. 157). The belief that women’s physical capabilities are limited and should be focused on childrearing could be traced back to historical understandings of women’s bodies as enfeebled by menstruation (Vertinsky 1987).

Hegemonic femininity ‘has a strong emphasis on appearance with the dominant notion of an ideal feminine body as thin and toned’ (Krane et al. 2004, p. 316). Grogan et al. (2004, p. 50) write that ‘women
who aim for a muscular physique are transgressing current Western cultural norms’ (Grogan et al. 2004). As such, being ‘athletic’ and ‘toned’ are more feminine-appropriate goals (Bordo 1993). Further, the demeanours that are often performed when negotiating a weight room – competitiveness, independence, assertiveness and strength – run contrary to traditional ideas of femininity (Krane et al. 2004). Likewise, when lifting weights, ‘maximum effort and noise’ are associated with masculinity, while ‘the association of contained effort and silence with the feminine’ (Brace-Govan 2004, p. 523), even though the latter is not always conducive to the strength training routines recommended for women with PCOS.

Much of the previous research on women and weight lifting has examined those who arguably challenge the gendered nature of strength training and subvert expectations: female bodybuilders and competitive weightlifters. In Grogan et al.’s (2004, p. 57) study of female body builders, the study’s participants experienced improved self-esteem when they became stronger and more muscular. ‘All of the women we interviewed said that they felt more confident and able to cope with challenges in their lives once they started to build muscle’, the authors write. Additionally, the women in the study showed that ‘contesting the dominant slender ideal can lead to feelings of empowerment and the forging of alternative body ideals’ (p. 59). In Boyle’s (2005, p. 134) study of female body builders, one of her respondents said, ‘times have changed; they’re looking for a mixture of muscularity and femininity and you have to be able to have both and these girls have a hard time figuring that out’. She concludes that support for female bodybuilding is waning, and the future of the sport is in question due to the pressures put on women to teeter this difficult line. Boyle (2005, p. 146) writes that ‘the pressure faced by female bodybuilders to negotiate between projecting a sexually attractive athleticism and going “too far” is problematic. Arguably, this burden is not only felt by those who are competitive weight lifters, but also in those who are engaging in strength training for fitness and health-related purposes.

In Dworkin’s (2001, p. 337) qualitative study of women who lifted weights for fitness, she found that 75% of the women interviewed had a ‘shared explicit fear of and repulsion to female bodybuilders’ bodies and fear of becoming too big or bulky themselves’. Dworkin (2001) found that there were three categories of women that worked out at the gym: (1) non-lifters; (2) moderate lifters; and (3) heavy lifters. The majority of the women were categorised as moderate lifters, meaning they would occasionally lift light weights but not to the point of strain, or they would do bodyweight exercises such as sit-ups. Doing these types of exercises emphasises women’s desire to gain slight ‘tone’, while not becoming too muscular. Dworkin (2001) explains that there is a culturally produced glass ceiling on muscularity, meaning that emphasised femininity does not allow for overly muscular women, hence the women’s distaste for female bodybuilders in her study. Women with PCOS must mute culturally amplified voices in their heads telling them not to get ‘too muscular’, challenging gendered norms in order to regain a sense of feminine agency in the form of improved fertility and minimised stereotypically masculine facial features.

For those who are coping with PCOS, the loaded tensions arising from gendered expectations can be particularly challenging. These women have ‘masculine’ symptoms they must work to combat, all while engaging in this ‘masculine’ routine. Yet, the feelings of empowerment that can arise from high-effort strength training can be a tangible benefit at a time when it is especially needed and beneficial.

**Muscle as medicine: benefits and drawbacks**

Researchers in the past have emphasised the importance of assessing the mental health of women with PCOS in order to monitor signs of depression, anxiety and other mental disorders. Yet, little has been said in terms of possible ways in which women with PCOS, grappling with strained feelings of guilt, pity, uncertainty, lack of control and loss of femininity, can work to improve their psychological well-being. How are women with PCOS to cope with these layers of complex emotion? Coping is a term used widely in chronic illness literature, and it encompasses a range of illness-related experiences including developing a sense of self, tolerating symptoms and matters of disclosing an illness to others (Kelly 1994, Bury 2001). Coping is characterised as the way that people maintain a sense of self-value, even when dealing with interruptive symptoms and other difficulties of chronic illness (Bury 1991). Frank (1997, pp.
writes that people with illness strive to be ‘successfully ill’ and those who are dealing with an illness are presented with a ‘moral opening for witness and change’. The autoethnography presented in this article provides empirical evidence for the ways in which strength training in particular can be empowering for women with PCOS, and can be used as a way of coping with this condition – both its symptoms and its backhanded consequences. As such, women perform the ‘successfully ill’ patient role by taking over their condition via engaging in health lifestyles.

PCOS is not a universally experienced condition, but teaching patients to frame exercise as medicine may be a generalisable treatment plan that can empower patients with different symptomatic realities. As Dworkin (2001, pp. 334, 335) concludes in her study of women weight-lifters, ‘heavy lifters experienced sport and fitness as sites of power and agency where they have rejected narrow constructions of femininity and where they can embrace physical power and independence’. We should view weight training as a dually beneficial activity: it can aid women with PCOS in curbing their physiological symptoms stemming from the condition, and can also help women with secondary psycho-social issues they are coping with, particularly as they pertain to challenging and taking back the notion of what it means to appropriately enact femininity.

Despite the benefits of framing muscle as medicine, encouraging medical practitioners to prescribe exercise routines can be a slippery slope, as it imposes an obligation onto patients who may not be able to easily adopt a new physical activity regimen. Personal responsibility has its limits. Having the belief that you have control over your well-being is arguably part of what Bourdieu (1984) calls habitus, or the interplay between structure and agency. Habitus encompasses components of lifestyle, such as particular tastes, dispositions and preferences in activities. We can only pursue activities that we frame as a possibility for members of our reference groups. Medical professionals need to consider issues surrounding habitus – the choices we can make out of the options given – and thereby, be sure to give options for strength training that can be done without a gym membership or a great number of resources.

Routinised exercise is a marker of cultural capital, as tastes in sports and health activities reflect social class and sensibilities (Bourdieu 1984). As a highly educated, middle-class, medical sociologist, I have access to the educational, institutional, economic and cultural capital necessary to pursue a regular weight training regimen. Over the course of my life, I have had opportunities to strength train in gym class and with my athletic teams, so lifting weights was not a brand new endeavour for me when I was diagnosed with PCOS. Likewise, I was not as afraid of building muscle or appearing overly ‘masculine’ because I was immersed in an athletics environment and surrounded myself with muscular women during my college athletics career. For those living within similar opportunity structures, framing muscle as medicine can have its benefits in ways that go beyond lowering blood sugar and improving body composition. However, for those living with more disadvantage and fewer resources, framing muscle as medicine may add undue stress and burden. Future research can work to come up with ways to empower those whose social class and sensibilities may not as easily adhere to the quick adoption of a weight training regime. This could come in the form of sending patients home with exercise DVDs, hand weights, exercise bands or a pamphlet of exercises to show them how to build muscle at home. Likewise, older adults should be given recommendations that accommodate any physical limitations. If insurance companies covered basic gym memberships or exercise classes that cater to specific populations (e.g. older adults, women) that could also benefit a great number of patients whose chronic conditions could improve with an exercise regimen.

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