



## Review

# At the Heart of Resilience: Empowering Women's Agency in Navigating Cardiovascular Disease

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### ABSTRACT

Cardiovascular disease (CVD) is the leading cause of death among women globally, emphasizing the need for a healthcare approach that empowers women through agency. This review focuses on the critical role of women's agency in navigating CVD, integrating insights from various fields, including medicine, education, psychology, and sociology. The review highlights the shift toward patient-centred care, a framework in which women are recognized as key decision-makers, a crucial change given the historical underemphasis on women's health issues in medical practice. The diagnosis of CVD in women often involves emotional and psychological challenges. Unexpected diagnoses significantly disrupt perceived well-being, and prolonged diagnostic processes lead to professional skepticism and neglect of symptoms, resulting in delayed or inaccurate diagnoses and strained healthcare relationships. Effective management of CVD necessitates continuous

### RÉSUMÉ

Les maladies cardiovasculaires (MCV) sont la principale cause de décès chez les femmes dans le monde, ce qui souligne la nécessité d'une approche de soins de santé qui responsabilise les femmes et favorise leur agentivité. Le présent article de synthèse porte sur le rôle crucial de l'agentivité des femmes dans leur parcours avec les MCV, et il intègre des renseignements provenant de diverses disciplines dont la médecine, l'éducation, la psychologie et la sociologie. Nous soulignons le passage vers un modèle de soins centrés sur la personne dans lequel les femmes sont perçues comme des preneuses de décisions clés. Cette approche marque un changement important, dans un contexte où une faible importance a historiquement été accordée aux problèmes de santé des femmes dans la pratique médicale. Le processus diagnostique des MCV chez les femmes comporte souvent des défis émotionnels et psychologiques. Les diagnostics inattendus

### Lay Summary

*Heart disease, the number one killer of women globally, requires healthcare that lets women take ownership of their health. This review emphasizes empowering women in managing their heart health, combining insights from various fields. The review underscores the need for a patient-focused approach that recognizes women as decision-makers and addresses the emotional and psychological aspects of heart disease diagnosis and treatment. The review advocates for healthcare systems that support women's active participation and autonomy in their health journey.*

### Prologue

Overwhelmed by a sudden, extensive tingling sensation, I sensed something was amiss. As I stumbled towards the bathroom, a disconcerting weightlessness took over, sparking fear and denial. My body wouldn't cooperate; speaking

became an impossible task, a numbness took over my right arm, and a terrifying disconnect between my brain and body set in.

*What is happening?*

For 5 years, I had battled heart failure, yet denial clouded my acceptance that it might be the culprit again. The initial diagnosis had been a shock, and the subsequent years were no less challenging.

*Please, not again!*

My husband, Nick, swiftly called 9-1-1 for emergency medical help, informing the EMTs [emergency medical technicians] of my heart failure history and requesting an ambulance to my preferred hospital. As the EMTs briefed the hospital staff on my condition, my memories became jumbled.

*Is this my fault?*

The fear of a stroke haunted me, recalling an earlier aphasia episode and a dizzy spell I had dismissed as dehydration.

*Should I have spoken up?*

In the emergency department, the fear of lying down, reminiscent of my pre-diagnosis congestion, was overwhelming. Despite comprehensive evaluations and consultations with neurology and cardiology, my terror persisted.

*They will help me, I assured myself.*

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self-management and a holistic approach to care, particularly for those with trauma who are at increased risk of cardiac incidents. Empowerment for women with CVD involves promoting self-confidence, autonomy, and active patient participation in healthcare. Implementing comprehensive care models is crucial for improving chronic CVD management, highlighting the need for healthcare systems that prioritize patient agency and empowerment. From the perspective of a woman with lived experience, this article examines the impact of CVD on women's agency throughout the diagnostic journey. By highlighting women's agency rather than particular behavioural changes, this review offers a comprehensive analysis that can shape policy, stimulate new research, and foster a more equitable, efficient, and empathetic healthcare system for women with CVD.

Unable to stay still for the CT [computed tomography] scan, I was given lorazepam, which calmed me enough to undergo the procedure, though my recollection of it remains unclear, clouded by fear. After several hours, the conclusion was an anxiety attack; I was sent home with lorazepam and instructions to rest.

*Why can't I speak or move my arm properly?*

Back home, my condition unchanged, I reached out to my heart failure team. They immediately conducted further tests, revealing a dramatic drop in my ejection fraction (EF) and significant clot formation in my heart. My treatment shifted urgently: warfarin, referral for an implantable cardioverter defibrillator (ICD), and a neurology follow-up. Subsequent neurological assessments uncovered that I did indeed have a stroke. An MRI [magnetic resonance imaging] scan shows an evident 3-cm lesion behind my left ear.

*How could they miss this!? Aphasia and a dead right arm, classic symptoms of a stroke.*

*Why didn't they check my heart with my history of heart failure?*

*How could a trained neurologist send me home with a diagnosis of an "anxiety attack!"?*

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My narrative is not unique; women with cardiovascular disease (CVD) like myself are often misdiagnosed or sent home prematurely from emergency departments (EDs).<sup>1,2</sup> The journey with CVD is chronic, a lifetime of engaging with the healthcare system often fraught with issues and potentially traumatic touchpoints.<sup>3</sup> This article examines the critical need for individuals, particularly women, to cultivate agency, enhance health literacy, and practice self-advocacy and help-seeking behaviours as essential strategies for managing CVD as a chronic condition.

## Introduction

Cardiovascular disease (CVD) is the leading cause of death for women globally.<sup>4-6</sup> Heart failure, a frequent result of CVD, is not only as devastating as cancer but carries a worse

perturbent considérablement la perception de bien-être, et les processus de diagnostic longs donnent lieu au scepticisme professionnel et à la négligence des symptômes, ce qui peut causer des retards ou des erreurs de diagnostic et des relations tendues avec les professionnels de la santé. La prise en charge efficace des MCV fait appel à une autogestion continue et à une approche holistique des soins de santé, en particulier pour les personnes ayant vécu des traumatismes et qui sont exposées à un risque accru de manifestations cardiaques. La responsabilisation des femmes atteintes de MCV passe par la promotion de la confiance en soi, l'autonomie et la participation active des patientes dans leurs soins de santé. La mise en œuvre de soins complets est déterminante pour améliorer la prise en charge des MCV chronique, et les systèmes de soins de santé doivent donc placer l'agentivité et l'autonomisation des patients au premier plan. Du point de vue d'une femme ayant une expérience personnelle de la réalité des MCV, le présent article examine ses répercussions sur l'agentivité des femmes tout au long du processus diagnostique. En soulignant l'agentivité des femmes plutôt que certains changements comportementaux, notre article de synthèse offre une analyse globale susceptible d'influencer les politiques, de stimuler la recherche et de favoriser des systèmes de santé plus équitables, efficaces et empreints d'empathie envers les femmes atteintes de MCV.

prognosis, with a staggering  $\approx 50\%$  mortality rate within the first 5 years.<sup>7-9</sup> Women make up more than half the population, yet significant shortcomings in understanding women's health and CVD care remain prevalent.<sup>10</sup> These shortcomings contribute to ongoing challenges in clinical management, which may be attributed to the underrepresentation of women in CVD research.<sup>4,11</sup> Women's CVD symptoms are often more subtle and may differ from men's, leading to potential misdiagnoses or underdiagnoses.<sup>12</sup> Women living with CVD may experience a medical journey characterized by frequent emergency visits,<sup>2</sup> early dismissals by care providers,<sup>1</sup> and increased fear of misdiagnosis,<sup>13</sup> which ultimately can leave them traumatized.<sup>3</sup> These experiences highlight women's challenges within a system that inadvertently restricts their autonomy and agency.

Agency is the ability of individuals to make decisions and act in ways that influence their lives, affecting how they use their freedom to address their well-being proactively.<sup>14-17</sup> These freedoms include choosing health behaviours, deciding on treatment options, and navigating the healthcare system.<sup>18,19</sup> This review aims to outline how understanding a woman's sense of control—or agency—over their health is of paramount importance in the care and management of women with CVD.<sup>20</sup> This review offers a unique and comprehensive perspective on agency's vital role for women facing CVD, providing evidence and synthesizing insights from medicine, education, psychology, and sociology.<sup>2,13,21</sup> First, from the perspective of a woman with lived experience (WWLE), this article explores women's agency and autonomy through empowerment, emphasizing the holistic well-being of women rather than focusing strictly on the disease. Next, this article examines the effect of CVD on women's agency throughout the diagnostic journey. Finally, this article offers strategies for caregivers to use to empower women by addressing the intricate interplay of psychosocial factors, health literacy, and shared decision-making (SDM) in clinical environments.

## Empowering Women's Agency

Engaging patients as agents to participate in decision-making leads to their being more empowered in undergoing healthcare experiences.<sup>20,22</sup> The provider-patient power dynamic can inhibit or enhance patients' sense of control (agency), impacting their confidence (self-efficacy) to make informed treatment decisions.<sup>23</sup> Empowerment is a motivational construct that positions patients as independent agents in their healthcare decisions, leading to a greater sense of responsibility for those decisions.<sup>24</sup> Empowerment includes the following: (i) meaningfulness—that is, how important one's actions feel; (ii) competence—that is, believing in one's skills; (iii) impact—that is, feeling like one can change things; and (iv) self-determination—that is, making choices on one's own.<sup>24</sup> In a recent systematic review, Náfrádi et al. examine how empowerment affects medication nonadherence—the extent to which patients take medication in ways other than those prescribed by their healthcare providers.<sup>22,25</sup> They found that high levels of self-efficacy<sup>26</sup> (competence) and internal locus of control<sup>27</sup> (self-determination) consistently promoted medication adherence. Náfrádi and colleagues further highlight the importance of shared understanding between the doctor and patient concerning the patient's control over managing their disease.<sup>22</sup> Reframing the CVD narrative to incorporate an empowered-patient perspective requires examining agency, as individuals transition from personhood to patienthood within the doctor-patient power dynamic and in SDM and participatory care.

## Becoming a patient: from personhood to patienthood

Seeking help from a healthcare professional automatically categorizes you as a patient, a label that carries significant weight.<sup>28</sup> Oliver Sacks describes this weight as an “organically determined erosion of *being* and *space*” that leads you to “surrender to ‘them’ — ‘them’ being the surgeon, the whole system, the institution.” Through this process, you enter “*patienthood*.”<sup>29</sup>

Agency, personhood, and patienthood are interconnected concepts with distinct meanings in philosophy, ethics, and healthcare. Personhood focuses on the qualities that define an individual as a person,<sup>30,31</sup> whereas patienthood encompasses the experiences of individuals receiving medical care.<sup>32-34</sup> In a shift from earlier views of patients as passive, as illustrated earlier, contemporary perspectives, influenced by authors like Entwistle and Watt, now recognize patients as agents and active collaborators in their care, fully acknowledging their humanity and personhood.<sup>20,35</sup> However, this shift from personhood to patienthood highlights how one's inherent rights and characteristics intersect with the healthcare system, underscoring the importance of patient agency in the doctor-patient power dynamic.<sup>36,37</sup>

## Doctor-patient power dynamic

A reevaluation of the doctor-patient power dynamic in clinical practice has driven recent policy shifts toward patient-centred care.<sup>35,38,39</sup> Proactive patient participation in healthcare challenges established biases and can ensure that women's health priorities receive recognition.<sup>40</sup> Historically, women's medical needs often have been viewed and addressed from a

male perspective. Feminist cultural historian Elinor Cleghorn<sup>41</sup> writes:

For centuries, medicine has claimed that women are defined by their bodies and biology. But we have never been respected as reliable narrators of what happens to our bodies. We are denied agency because the man-made world privileges specialist, sanctioned knowledge over our own thoughts and feelings. There is no space in the professional narrative of illness and disease for women's own experiences.<sup>41</sup>

Although most doctors do not intentionally disregard women, historically, women's diseases have not been prioritized.<sup>41,42</sup> Therefore, enhancing women's agency in the doctor-patient relationship by incorporating individual narratives is crucial and fosters a deeper understanding of their life contexts and preferences.<sup>38</sup> Despite the potential of women being labelled as “difficult patients,”<sup>43,44</sup> this approach will restore the power imbalance by empowering women to direct their health journeys through self-advocacy.<sup>26,45</sup>

Self-advocacy is crucial in navigating the complexities and potentially disempowering nature of medical encounters.<sup>38,40,46</sup> By exercising agency, women enhance and personalize their care, potentially driving a paradigm shift in the medical community's approach to female-specific CVD, promoting equity and reducing healthcare disparities.<sup>47</sup> A participatory healthcare environment in which doctors and patients form a collaborative relationship characterized by mutual respect and shared responsibility is essential in managing chronic diseases such as CVD.<sup>48</sup>

## Informed consent and participatory care

Embedded in Western bioethics, the principles of self-determination and well-being actively counter medical paternalism, reinforcing patients' rights to informed consent or refusal.<sup>49</sup> This dynamic between individual agency and consent safeguards against coercion, ensuring that women, as patients, receive thorough information about their diagnosis, treatment options, risks, benefits, and alternatives.<sup>50-53</sup> This approach empowers women to make well-informed healthcare decisions, increasing their autonomy. Increasing and respecting individual autonomy focuses on the importance of independent living and the decision-making that leads to certain choices.<sup>54</sup>

Autonomy is fundamental to informed patient choice. Sandman and Munthe's study entitled “Shared Decision-Making and Patient Autonomy” underscores the importance of autonomy in SDM. The authors discuss different aspects of autonomy relevant to SDM, including self-realization, preference satisfaction, self-direction, binary autonomy of the person, and gradual autonomy of the person.<sup>54</sup> Self-realization in SDM refers to the ability of individuals to make and act on choices that reflect their preferences, beliefs, and values. This ability requires the mental capacity to understand information and make informed decisions, ensuring that individuals have real options that are not restricted by their circumstances.<sup>54</sup> Preference satisfaction, in SDM, is how well the decision-making process matches the patient's preferences and values. Self-direction is the patient's ability to make healthcare decisions based on their genuine preferences and decision-making capacity. This concept highlights the patient's

autonomy and agency in their healthcare choices, independent of the outcomes. Binary autonomy refers to the basic level of self-direction, with which individuals can make choices and guide their own lives<sup>54</sup>; it is seen as a fundamental component of personal autonomy. Gradual autonomy describes the process by which individuals enhance their ability to self-direct by strengthening their capacities and improving their circumstances over time.<sup>54</sup> Sandman and Munthe argue that boosting self-realization requires promoting self-direction, preference satisfaction, and binary autonomy, with gradual autonomy playing a key role in enhancing these elements. They advocate for shared rational deliberative patient choice and joint decision as the preferred SDM approaches for supporting autonomy and agency.<sup>54</sup> Empowering individuals with CVD with agency will ensure alignment of CVD treatment decisions with their rights, values, and preferences, reflecting their personal beliefs and circumstances.<sup>41</sup> Exploring agency and autonomy in this context sheds light on the importance of understanding the lived experience in SDM once a diagnosis of CVD is obtained. However, the lived experience of the diagnostic process, particularly for women, is shaped by social experiences both within and beyond the healthcare domain.

## From the Lived Experience of Having Cardiovascular Disease

### Diagnostic journey

Diagnosis occurs at a salient juncture between illness and disease, patient and doctor, complaint and explanation.<sup>55</sup> The diagnostic journey is an overlooked period in the illness experience, when patients begin to test self-management strategies, develop relationships with healthcare providers, and intimately interact with healthcare institutions.<sup>55,56</sup> As Figure 1 illustrates, the illness experience occurs long before

patients achieve diagnostic labels, profoundly shaping how patienthood is practiced.<sup>21</sup>

Sociologists have studied the diagnosis process and personal illness narratives extensively.<sup>33,57-59</sup> Jeske et al. describe a “regimes of patienthood” framework that uncovers the interplay between diagnostic pathways, power dynamics, and personal agency in shaping illness experiences and patient roles. Jeske’s team identifies 3 diagnostic categories: sudden diagnoses, prolonged diagnostic journeys, and cases marked by skepticism and care denial.<sup>33</sup> Their research emphasizes the significant influence of the diagnostic process on patient perceptions and management of their conditions, with a notable impact on those with medically unexplained symptoms.<sup>34</sup> Jeske and colleagues’ research offers crucial insights into women’s experiences with CVD, which we examine closely using their diagnostic typology.

**Process 1: Sudden diagnosis.** An unexpected CVD diagnosis, often resulting from a sudden cardiac event, can catch patients off guard, contrasting sharply with the patient’s previous sense of well-being, leading to emotional and psychological distress.<sup>33,60,61</sup> After this sudden diagnosis, patients may face an overwhelming number of medical appointments and treatments, eliciting mixed emotions, conflicting beliefs, and cognitive dissonance.<sup>62-64</sup> Such a rapid medical process can hinder patients’ complete understanding of their condition, potentially resulting in their having persistent feelings of powerlessness and diminished agency.<sup>65</sup> The contrast between the immediate impact of a sudden CVD diagnosis and the prolonged uncertainty of an extended, changing diagnostic process underscores the diverse challenges patients face, from acute distress to enduring ambiguity in their healthcare journey.<sup>61</sup>

**Process 2: Long, changing diagnostic journeys.** Patients experience an extended period of uncertainty in the second

## Life Before Diagnosis



**Figure 1.** A representation of Canadian women’s uncertain journeys with cardiovascular disease before diagnosis. Adapted from the “Patient Journey Map”<sup>21</sup> with permission from the HeartLife Foundation of Canada.

diagnostic category, often enduring years of searching for a diagnosis.<sup>33,34</sup> These individuals typically present with ambiguous symptoms, resulting in prolonged diagnostic procedures. During this period, they may encounter “provisional diagnoses” that lead to various potential treatments. Without a definitive diagnosis, the focus turns to symptom management, and prevention of further health decline. This cycle of testing, treatment, and ongoing uncertainty, as depicted in Figure 2, is a well-documented phenomenon in the medical literature.<sup>66</sup>

In this diagnostic category, some patients encounter skepticism from medical practitioners who may downplay or dismiss their symptoms, a situation frequently reported by WWLE.<sup>13,67,68</sup> This skepticism drives these patients to seek healthcare professionals who demonstrate greater empathy and collaboration, aiming to secure a definitive diagnosis.<sup>34</sup> Notably, many of these individuals begin self-advocacy prior to receiving an official diagnosis, extending their efforts beyond clinical settings. They often actively research their symptoms to uncover effective management strategies.

**Process 3: Diagnostic journeys marked by disbelief and denial of care.** The final diagnostic journey, marked by skepticism and care refusal, often involves medical professionals dismissing patient symptoms and pain, leading to delayed or missed diagnoses and strained healthcare relationships.<sup>16,69</sup> This delay results in lasting, traumatic effects on patients and their families, fostering distrust in the healthcare system. Particularly for women, this disbelief and denial of care can be profoundly disheartening, impacting their mental health, agency, and psychosocial well-being.<sup>70</sup>

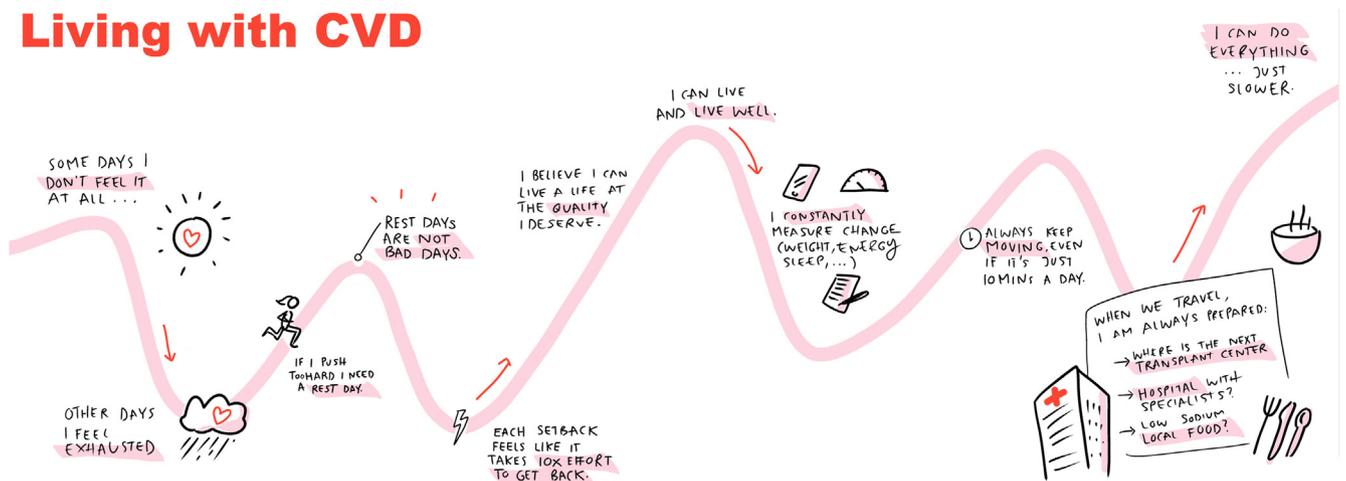
### Agency and psychological well-being in CVD

Managing a chronic condition such as CVD necessitates continuous learning and self-management to support psychosocial well-being.<sup>20</sup> Agency, increasingly recognized for its role in mental health and CVD management, is closely tied to psychological well-being, autonomy, and perceived control over the disease.<sup>71,72</sup> Research underscores the importance of

exploring beliefs about control, in relation to the risk of mortality and major cardiovascular events.<sup>73,74</sup> Perceived control is a strong independent predictor of CVD mortality and may be considered a CVD risk factor.<sup>75</sup> Further investigation is required to ascertain its influence on patient engagement with healthcare systems and individual responses to clinical treatments.<sup>73,75</sup> This need for a deeper understanding of the impact of beliefs about control on patient behaviour and treatment response becomes particularly pertinent in light of recent findings linking chronic medical conditions, such as CVD, with a significant rise in the likelihood of concurrent psychiatric disorders. A study of community respondents found that people suffering from 1 of 8 medical disorders, including CVD, had a 41% increase in the relative risk of having any recent psychiatric disorder, compared to people without chronic medical disorders.<sup>76,77</sup> This correlation between chronic medical conditions and heightened psychiatric risk is further emphasized by the specific case of posttraumatic stress disorder (PTSD), in which sufferers experience a markedly increased risk of cardiac incidents and mortality, distinct from the influence of depression.

Individuals with PTSD face a 53% increased risk of cardiac incidents or mortality, a risk that remains significant at 27%, even after accounting for depression.<sup>78</sup> This heightened risk is explored in a systematic review and meta-analysis by Edmondson and Von Känel, who explore the connection between PTSD and acute cardiac events and cardiac-specific mortality.<sup>78</sup> They distinguish cardiac disease-induced (CDI)-PTSD, which is triggered by the fear of recurring cardiac events and heightened bodily awareness, from PTSD caused by external trauma. Patients with CDI-PTSD often adopt unhealthy lifestyles and may neglect cardiac treatments, thus elevating their risk of subsequent cardiovascular events. Implementing a trauma-focused approach could be beneficial in treating CDI-PTSD and others, improving their overall psychosocial well-being.<sup>3</sup>

Trauma-informed care, emphasizing holistic well-being, aims to protect trauma-exposed individuals from retraumatization and blame.<sup>79</sup> Reeves highlights in a review that patients with



**Figure 2.** A representation of the cyclical, ambiguous journey as patients go through rounds of testing, treatment, and uncertainty. Adapted from the “Patient Journey Map”<sup>21</sup> with permission from the HeartLife Foundation of Canada. CVD, cardiovascular disease.

traumatic experiences, such as sudden or misdiagnosed cardiac events, may face distress or retraumatization in healthcare settings.<sup>79</sup> Recent studies also link childhood trauma to a higher risk of cardiovascular disease (CVD) in adults, particularly in women with increased cumulative childhood trauma.<sup>80</sup> Despite the commonality of traumatic experiences, trauma-informed care remains underresearched and under-implemented.<sup>80</sup> Implementing this approach could help reduce health disparities and care barriers.<sup>81</sup> Moreover, for patients with CVD, agency is particularly vital, as it plays a significant role in reducing stress and associated CVD risks, thereby improving health outcomes for individuals managing the disease.<sup>82</sup>

**Living with CVD**

Beyond the diagnostic process and the continuous cycle of medical appointments and tests, WWLE must navigate life with CVD. A CVD diagnosis requires significant adjustments to daily life and increased attentiveness to physical signals.<sup>66</sup> For example, The HeartLife Foundation of Canada conducted a qualitative study capturing the experiences of Canadians living with heart failure.<sup>21</sup> In an adaptation from the report, Figure 3 illustrates the realities of living with heart failure as an up-and-down daily journey echoed across the chronic disease literature.<sup>66,83</sup>

Individuals with heart failure and CVD often experience varying physical and emotional states, alternating between symptom-free days and periods of intense fatigue. As depicted in Figure 3, patients typically self-manage by categorizing their days as “good,” “bad,” or “rest days,” understanding that rest is crucial for overall well-being and is not a setback.<sup>21</sup> The Spoon Theory, introduced by Christine Miserandino in 2003, effectively illustrates the energy limitations faced by those with chronic illnesses or disabilities. The theory compares daily tasks to a limited number of “spoons,” representing units of

energy, underscoring that rest is essential for energy replenishment.<sup>84</sup> Managing CVD is a dynamic, complex process that involves agency, encompassing acceptance of the condition, development of coping strategies, mastery of self-care, integration of the illness into daily life, and adaptation to necessary lifestyle changes.

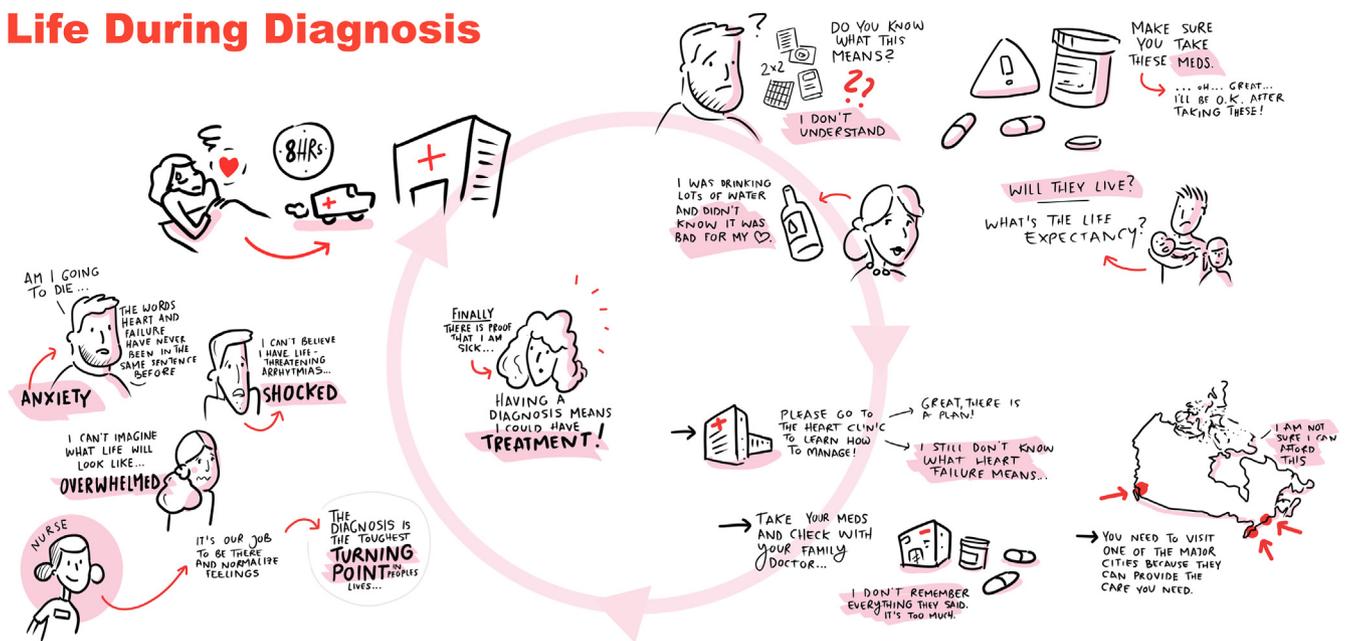
**The Importance of Women’s Agency in Health**

Patient-centred care recognizes health agency as its core component,<sup>26,45</sup> aligning with Canada’s emphasis on an individual’s right to universal healthcare.<sup>85</sup> Empowering women to make autonomous healthcare decisions is critical for enhanced health outcomes, and research suggests that augmenting women’s agency correlates with improved health indicators.<sup>87-89</sup> Prata et al. documented that women’s autonomy in reproductive health choices notably elevated maternal and child health outcomes,<sup>89</sup> and Kim and Rich indicate that women who are actively involved in their healthcare choices adhere better to treatment plans, subsequently witnessing more positive CVD results than those who are less proactive.<sup>90</sup> Similarly, Chen et al. highlighted that women exhibiting a higher level of health agency tend to adopt preventive measures more, leading to diminished CVD risks.<sup>12,91</sup> This emphasis on health agency in patient-centred care, particularly for women’s health outcomes, seamlessly leads into the broader concept of empowerment, which encompasses psychological, social, and economic dimensions and is fundamental in navigating and overcoming challenges such as CVD.

**Empowerment in treatment strategies**

Empowerment is a multifaceted concept integrating psychological, social, and economic elements aimed at guiding

**Life During Diagnosis**



**Figure 3.** A representation of the patient’s journey with cardiovascular disease. Adapted from the “Patient Journey Map”<sup>21</sup> with permission from the HeartLife Foundation of Canada.

individuals towards self-confidence, autonomy, and assertion of their rights. Being empowered is taking a proactive approach to effecting social change by utilizing personal strengths and abilities.<sup>92,93</sup> Kabeer emphasized empowerment as a tool for enabling choice and goal achievement in those previously lacking such opportunities.<sup>86</sup> This view is in line with Malhotra et al.'s economic perspective, which considers empowerment as a means to address entrenched economic and sociopolitical disparities.<sup>94</sup> Thus, empowerment is crucial for fostering individual autonomy and surmounting barriers to personal objectives, such as a CVD diagnosis, effectively bridging psychological resilience with socioeconomic progress.<sup>86,92,94</sup> Building on the concept of empowerment, particularly in healthcare, the shift to a patient-centric model exemplifies how empowering patients is instrumental in achieving optimal health outcomes. The diagnosis of a chronic disease such as CVD often has profound implications for an individual's mental health, as it is frequently accompanied by a lessening of personal agency.

### When agency is taken away

A chronic disease diagnosis can precipitate a sense of loss of control and a sense of unpredictability, which are key factors contributing to mental health challenges such as anxiety and depression.<sup>95</sup> This psychological impact is compounded by the need to navigate a complex healthcare system and adhere to a potentially demanding treatment regimen, which can exacerbate feelings of helplessness and dependency.<sup>76</sup> Furthermore, the shift in identity from that of a healthy individual to that of a patient often necessitates a reevaluation of self-concept and future plans, contributing to distress and uncertainty.<sup>96</sup> In addition, chronic illness can impose social and occupational limitations, further eroding a sense of agency and leading to social isolation and reduced quality of life.<sup>97</sup> For many, especially women, these effects are intensified by preexisting societal biases and disparities in healthcare access and treatment, which can further inhibit their ability to advocate for their needs and preferences within the healthcare system.<sup>98</sup> When individuals are diagnosed with a chronic disease, fostering patient agency can have a significant positive impact on their mental health.

### When agency is promoted

When patients are encouraged to participate actively in their care, they often experience improved mental health outcomes. Patient empowerment, an essential aspect of agency, is associated with reduced anxiety and depression, as it provides patients with a sense of control over their illness.<sup>20,22</sup> Involvement in treatment decisions and self-management strategies can increase self-efficacy, which is linked to better adjustment to chronic disease and improved psychological well-being.<sup>99</sup> Additionally, patient-centred care, which emphasizes respecting and responding to individual patient preferences, needs, and values, has enhanced patient satisfaction and quality of life, positively influencing mental health.<sup>39</sup> This approach not only mitigates the feelings of helplessness and dependency that are often associated with chronic illness but also fosters resilience and adaptive coping mechanisms.<sup>100</sup>

Patient agency is crucial for customizing treatments to individual CVD care and management needs.<sup>101</sup> Active

patient engagement facilitates effective communication of distinct symptoms, personal experiences, and lifestyle considerations, which are critical for addressing CVD's diverse manifestations and outcomes.<sup>10</sup> Thus, agency enables healthcare providers to understand patient-specific details, leading to more individualized and effective treatment plans.<sup>10</sup> As CVD care evolves toward greater personalization, leveraging patient agency ensures clinical effectiveness, and unity with the patient's values, preferences, and life circumstances.<sup>102,103</sup> The importance of patient agency in individualized CVD care extends beyond treatment personalization to encompass a broader spectrum, particularly in health literacy among women with CVD.

### Agency and improved health literacy

Agency plays a crucial role in enhancing health literacy among women with CVD. Health literacy involves accessing, understanding, evaluating, and utilizing health information for making informed health decisions. Sentell et al. found that women who actively engage in their healthcare decisions, demonstrating agency, are more adept at seeking, understanding, and applying health information pertinent to their conditions, such as CVD.<sup>104</sup> This engagement typically leads to improved knowledge about their disease and its management. Recognizing the integral role of agency in health literacy, we can see how it explicitly influences women's engagement and understanding in managing conditions such as CVD, leading to a cycle of enhanced knowledge and health literacy.

Health literacy is dynamic, evolving through personal experiences and interactions with the healthcare system.<sup>105,106</sup> Women who exercise agency tend to engage more with healthcare professionals, participate in health-related discussions, and attend educational or support programs.<sup>107</sup> In this ongoing cycle of engagement and learning about managing CVD, a condition with numerous risk factors and treatment options, agency-driven health literacy is essential.<sup>104</sup> Health literacy not only aids patients in adhering to treatment plans but also empowers women to make lifestyle choices beneficial for their cardiovascular health, narrowing the knowledge gap. The dynamic nature of health literacy, particularly in women with CVD, underscores the necessity for healthcare models similar to the Chronic Care Model (CCM) that can enhance patient agency and informed participation in long-term care management.

### Agency in clinical care

Implementing a CCM in primary healthcare significantly improves chronic care management, particularly for women with CVD.<sup>108</sup> Enhancing CCMs to foster patient agency and empowerment is essential, as it enables patients to participate actively and make informed decisions in their care, a key factor in improving long-term CVD outcomes.<sup>109</sup> Care should be based on patients' lived experiences, helping them to overcome barriers to active engagement in their healthcare.<sup>108</sup> The empowered patient is central to the CCM, emphasizing enduring relationships with primary care physicians, improved care coordination, and a framework in which physicians are accountable for the holistic well-being of their patients.<sup>110</sup> These principles are both theoretical and practical tools for empowering patients to direct their health outcomes.<sup>111</sup> This approach would foster a multidisciplinary

team, on which each member recognizes the value of patient experiences and insights and operates from a position of empowerment and agency.<sup>112</sup> However, a need remains for research and implementation of CCMs that specifically cater to the unique experiences and needs of women with CVD.<sup>110,113</sup> Grover and Joshi observed that most CCM studies emphasize system design, clinician support, and health organization but seldom focus on patient and family involvement, patient safety, or integrated health.<sup>108</sup> Acknowledging the need to enhance CCMs toward more patient-centric care, particularly for women with CVD, is a recognition that patient empowerment is fundamental in forging a mutually respectful relationship between patients and primary care teams.

Effective implementation of the CCM in diverse settings is imperative to gain a deeper understanding and ensure a healthcare system that is both patient-centric and patient-directed.<sup>108</sup> This approach envisions chronic CVD management being shaped by the experiences and insights of people with lived experience, embodying patient empowerment and agency. By developing inclusive methodologies, patients become active directors of their health narratives, equipped with the knowledge and confidence to guide their healthcare journey. This patient-empowered approach is fundamental to a future healthcare system in which women are central figures in their health story, navigating it with knowledge, courage, ownership, and agency.

## Conclusion

Agency is crucial to empowerment, allowing individuals to assert their health needs and concerns.<sup>10</sup> Active involvement in healthcare decisions leads to better health outcomes, by promoting adherence to treatment plans, lifestyle changes, and preventive measures.<sup>114,115</sup> It also addresses systemic health disparities, especially for marginalized women, by providing them with the means to advocate for their health.<sup>16,116</sup> Personalized healthcare, crucial in modern medicine, benefits from agency, as it tailors care to individual needs and situations.<sup>117</sup> Empowering individual agency is essential for reducing stress and related risks, enhancing psychological health, and improving patient care outcomes.<sup>118,119</sup> Agency boosts psychological well-being by fostering self-efficacy and confidence, making healthcare experiences more positive.<sup>45</sup> Agency also enhances health literacy, as individuals are more likely to engage with health information, supporting informed consent and ensuring that patients understand their treatment options and agree with treatment decisions.<sup>105,106</sup>

This review offers a comprehensive analysis of the crucial role of women's agency in their health, specifically in managing CVD, from the perspective of a WWLE. The article synthesizes existing literature from multiple disciplines, highlighting implications for policy-making, clinical practice, and strategies to bolster women's agency in the context of CVD.<sup>13,21</sup> By prioritizing agency, rather than particular behavioural changes, this article advocates for healthcare reforms that can shape policy, stimulate new research, and foster a more equitable, efficient, and empathetic healthcare system for women with CVD.

## Epilogue

As I awaken from a nap, my eyes open to an unfamiliar hospital ceiling. Beside my bed, a window frames the vivid blue sky, a stark contrast to the hospital's bustling sounds—nurses in the hallway, the incessant beeping of machines. Here I am, on the edge of advanced heart failure, engulfed in a world that feels out of sync.

*Why am I here? Why is this happening to me?*

Amidst these thoughts, I find solace in my heart function team's decision. Despite my vitals appearing typical—albeit subpar—they sensed the need for further evaluation when I mentioned cognitive struggles. As an academic, losing focus was more than alarming; it was life-altering. Hence, I found myself admitted for tests, even facing the prospect of a heart transplant.

*A heart transplant. The thought alone is overwhelming.*

My cardiologists' entrance breaks my contemplation, their casual manner reminiscent of friends on a stroll. After initial niceties, they discuss my case. I might be on the transplant list soon but with a potential year-long wait. They suggest alternatives like a left ventricular assist device (LVAD) to improve my current state. The choice, they emphasize, is mine.

*I want to feel better, especially with such a long wait ahead.*

Choosing surgical intervention, I expressed my desire to improve my condition during the waiting period. I understand the benefits and risks and am ready for surgery. They respect my decision, seeing it as an informed choice in my healthcare journey. For my husband and me, my quality of life is our primary concern, a sentiment echoed by my medical team.

An agent initiates action, whereas a patient experiences its effects. In my journey, I transitioned from being a patient to becoming an agent. This transformation marked a transcendence beyond my role as just a patient, with an evolution into someone who also embodies the characteristics of an agent.<sup>120</sup> As an authentic agent, I am equipped to assertively articulate my needs, advocate for myself, and actively contribute to my care journey, bringing forward my experiences and feeling empowered to take ownership of "my broken heart."<sup>121</sup>

## Ethics Statement

This is a literature review and ethics review was not required. Experiences depicted in the Prologue and Epilogue are those of the author and are autoethnographic in nature meant to connect the lived experience of CVD to clinical research and practice in this special issue.

## Patient Consent

The author confirms that patient consent is not applicable to this article. This is a literature review and does not require IRB approval.

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The author has no conflicts of interest to disclose.

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