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## **A care pathway approach to identifying factors that impact on diagnosis of heart disease in British Pakistani Women**

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### **Abstract**

#### **Purpose**

We examined the cardiac care pathway to identify factors that impact on diagnosis and treatment of coronary heart disease in British Pakistani women. We used a pathways to care approach to illustrate how their individual and cumulative effect may contribute to differential receipt of treatment, including revascularisation, and health inequalities.

## **Design**

An exploratory qualitative study. In depth interviews and focus groups with an opportunistic sample of Pakistani women and a purposive sample of clinicians working at different points along the care pathway.

## **Findings**

Four major issues were identified: complex life circumstances; 'atypical' presentation and symptomatology; problems related to investigative testing; and poor communication. Mapping these barriers onto the Pathways to Care Model provided valuable insight into their impact on patients' progression through the different stages of the care pathway.

## **Research implications**

Adopting a care pathway approach demonstrated how individual factors have an impact at several points along the care pathway. It indicated where further, more detailed enquiry is merited and where intervention studies might usefully be directed to improve care.

## **Practical implications**

Examining the whole care pathway identified areas of service improvement that merit a co-ordinated response.

**Originality/value** The framework provided by the Pathways to Care Model offered insight into the causes of the previously observed attenuation in women's progress along the cardiac diagnosis and treatment pathway and is an important first step to addressing this health inequality in a holistic way.

Key words: Care Pathway, heart disease, Pakistani women, diagnosis, treatment

**Article classification:** Research paper

## **Introduction**

Coronary heart disease (CHD) is a major cause of morbidity (ONS 2010), particularly for those of South Asian origin. The lack of ethnicity recording at death registration precludes accurate CHD mortality estimates by ethnic group and inconsistencies in the ethnic categories used in studies further confuses the picture. Gill et al. (2002) analysed mortality data using country of birth to demonstrate that some South Asian groups – notably people born in Bangladesh and Pakistan – have elevated risks when compared to all people born in England. Harding, Rosato & Teyhan (2008) presented evidence to indicate that while CHD mortality rates have been falling among the majority White British population, declines have been slower in some groups, specifically men and women born in Pakistan and men born in Bangladesh. The first National Service Framework for CHD stated that 'for people born in the Indian sub-continent, the death rate from heart disease is 38% higher for men and 43% higher for women than rates for the country as a whole' (Dept of Health 2000, p7) and asserted the importance of addressing this through service improvement. As a preliminary to such work, it is important to examine the evidence concerning differential access to diagnosis and treatment.

A number of factors complicate the synthesis of existing evidence relating to heart disease and ethnicity in the UK; in particular the inconsistent (and often poorly articulated) use of ethnic categories and labels and the tendency in some studies to employ a broad 'Asian' or 'South Asian' category which conceals important heterogeneity of experience (Karlsen & Nazroo 2006).

Nevertheless, past research suggests factors that may contribute to poorer outcomes. First, the ways in which patients' presentation of symptoms, and particularly expressions of pain diverge from those regarded as 'typical' of heart disease and the consequent impact on diagnosis and treatment. Teoh et al (2007) report that a number of large scale studies found that, compared to (what they term) Caucasian patients, South Asian patients were more likely to use different descriptors to describe chest pain, had a more limited vocabulary of relevant words and phrases and were more likely to describe atypical distribution, direction and duration of pain. These differences were implicated in findings that reported a reduced likelihood that South Asian patients received a diagnosis of angina (Zaman et al. 2008) and experienced significant delays in the receipt of essential thrombolysis treatment (Barakat et al. 2003).

Second, hospital based studies conducted in the UK indicated differential access to investigation and treatment of heart disease with reduced likelihood of angiography and revascularisation in those belonging to South Asian groups compared to the White British population even when patients were deemed eligible on the basis of clinical assessment and where this was the physician's intended management strategy (Sekhri et al. 2008, Trevelyan et al. 2001, Feder et al. 2002).

Analyses by gender have revealed similar differences between the experiences of men and women in relation to both the presentation of the illness and receipt of intervention. Heart disease commonly presented atypically in women (Philpott et al. 2001, Ghezaljah et al. 2010) and was more likely to be associated with multiple symptoms including dizziness, weakness, nausea, dyspnoea, and palpitations (Bailey Merz et al. 2006, DeVon & Zerwic 2002), factors which will impact on initial diagnosis. When women were diagnosed with stable angina, they were less likely

than men to undergo non-invasive investigations, be referred for angiography and therefore proceed to revascularisation (Daly et al. 2006, Bowling et al. 2001, Britton et al. 2004). To-date, there has been little exploration of the intersection of gender and ethnicity in the diagnosis and treatment of CHD in the UK context although, local level audit data indicated particularly low rates of revascularisation in South Asian women which was identified as a cause for concern necessitating further enquiry (NHS Sheffield 2008).

Revascularisation is a treatment end point for CHD and many factors could contribute to differential rates by impacting on the diagnosis, care or management of patients with CHD. Research evidence to-date has tended to focus on particular parts of the pathway, and to describe observed differences rather than to explore underlying causes or to identify the potential for intervention to mitigate inequalities. This study adopts a more holistic approach. Using the Pathways to Care Model (Goldberg, Huxley 1992) as a framework, it seeks to explore factors that impact on women's journey through the care pathway as a basis to identify productive areas for service improvement.

The Pathways to Care Model is a framework for examining access to specialist services. It characterises the care pathway as a series of levels and filters; movement through which leads to increasingly specialised treatment and care. Selectively permeable filters operate between the levels and act differentially to influence the progress of individuals along the pathway. The framework was developed to identify variations in access to mental health care by analysing referral and attendance data at each service level for different populations (Hayward, Moran 2007) and has been subsequently developed and used more widely (Bower & Gilbody 2005, Sayal et al. 2002). We suggest that it can usefully guide a systematic

examination of the processes and factors that impact on diagnosis, treatment and care.

The CHD pathway can be constructed as a series of stages or levels that ultimately result in revascularisation. Focussing on each level in turn provides a basis for systematically identifying the filters that operate between those levels. Therefore, as well as identifying factors that impede movement through the pathway, it can also enable the identification of feasible points of intervention where barriers to effective care and treatment might be overcome. A schematic representation of the CHD pathway is presented in figure 1.

Using the Pathways to Care Model we set out to identify factors that may impact on the diagnosis and treatment of CHD in British Pakistani women drawing on data generated from the perspectives of the women themselves and clinicians involved in their care.

## **Method**

We conducted in-depth interviews with an opportunistic sample of six women aged 45-74 years (see table 1) who self-identified as being of Pakistani ethnicity and were suffering from CHD to capture their individual experiences of heart disease and healthcare provision. All six had been offered revascularisation. Four had undergone the procedure and two had declined.

Table 1. Demographic details of interviewees.

	45-49 years	50-59 years	60-69 years	70-74 years
Number of interviewees	1	2	2	1

Additionally we conducted two focus group discussions with an opportunistic sample of 13 ethnic Pakistani women aged over 40 years to gain insight into the general understandings of heart disease and the broader socioeconomic and cultural context that shapes healthcare experiences for these women and informed our analysis of the core data. All participants were recruited through community networks.

Interviews and group discussions were conducted in Urdu by an experienced female qualitative researcher of Indian background. Interviews were recorded, translated and transcribed in full. Names used in this paper are pseudonyms.

We used a purposive sampling approach to identify and recruit five senior clinicians. They were selected on the basis of their clinical role and place of work. Three worked in the cardiology service (1 senior consultant, 1 senior nurse and 1 senior physiologist) and two were community practitioners (1 GP and 1 Nurse Practitioner) both of whom worked in practices with a high proportion of Pakistani women. We used semi structured interviews to explore details of CHD care management and the specific issues associated with providing care for Pakistani women. Interviews were conducted by an experienced researcher and health professional. They were recorded and transcribed verbatim.

Data from both sources were analysed thematically. Transcripts were read and re-read. Initial coding and identification of themes were undertaken and agreed after discussion between members of the research team. This informed development of a



thematic framework and organisation of data in accordance with a framework analysis approach (Ritchie, Spencer 1994) using the Pathways to Care Model as a framework. An overview of the four themes is presented in Figure 2.

The project was categorised as service development and conducted in accordance with ethical principles set out in The Simple Rules Toolkit developed by the Sheffield Teaching Hospitals Trust (Somers et al. 2006). Ethical approval for the community level work was provided by a University Faculty Research Ethics Committee.

### **Findings**

Information generated from interviews with both the women and the clinicians highlighted the centrality of patient-provider interactions to the experiences and outcomes of healthcare for Pakistani women but also illustrated how these interactions are shaped by, and set within, the wider context of these women's lives. While the emphases were distinct in the two sets of data, both nevertheless revealed the vulnerability of the Pakistani women on the one hand and the inadequacies of the service provision for this group of patients on the other.

Three themes are presented in terms of how they impact at each stage of the pathway. Additionally, the fourth theme of 'life circumstance' runs through all the findings.

### **Delays in diagnosing heart disease in primary care (Filters 1 & 2)**

Failure of the women to respond to signs and symptoms of disease and ineffective communication between patients and clinicians appeared to contribute to delays to the diagnosis of heart disease.

The majority of the women reported delays in responding to angina symptoms because they were unaware of their possible significance and had disregarded them.

They did not perceive themselves to be at risk of disease and failed to recognise the symptoms in themselves even though three of them had cared for close relatives with the disease.

*I used to get breathless and had problems walking. I used to feel weight on this arm and pain here. I never thought that I had a heart problem. When my husband suffered a heart attack I never thought that I could suffer the same."(Farida)*

A further factor that discouraged the women from paying attention to their own health was their substantial family responsibilities and their instinctive prioritising of the demands of children, husbands and ill family members. Although this situation is not specific to Pakistani women, a number of factors - including the heavy burden of ill-health, rigid gender norms and expectations, and economic dependence - made these conflicting demands particularly acute in this group of women. As the women explained:

*"We take care of our children, clean the house, take care of clothes. Then we look after our husbands, cook for them. We neglect ourselves for our family; we finish ourselves."(Ayesha)*

*"My husband was hospitalized then and I had busied myself in taking care of him. It was not the right time for me to get it [angiography] done." (Nafisa)*

Significant transnational family ties also impacted on the women's ability to prioritise their health needs and family commitments which spanned two continents made it difficult for several of the women to respond promptly when health problems arose. Noor, who had her first angina attack whilst attending her father's funeral in Pakistan felt compelled to ignore medical advice to return home and seek treatment;

*"I did not want to leave Pakistan before performing all the last rites for my father .. I have a brother who has polio, he can't walk. I have a younger sister and a younger brother. I did not want my brother's wife to say that I abandoned all my responsibilities and went back selfishly. My sister used to cry a lot. I just could not see myself leaving my grieving mother and siblings behind."*

From the clinician perspective, diagnosing CHD in this group of women was identified as particularly challenging and under-diagnosis, particularly in primary care, was considered highly probable. One reason identified was that typical presentations of CHD are uncommon in Pakistani women. As the GP explained;

*"Very rarely will they come and say I've got chest pain'. They won't come and say I've got crushing chest pain, it comes on when I go uphill and it goes off when I stop."*

Another factor highlighted was the co-existence of other health problems which confuse the clinical picture. In the practitioners' experience, for Pakistani women with CHD, heart disease was unlikely to be their only health problem, unlikely to be the reason for their attendances at the GP surgery and unlikely to produce descriptions of classic angina. A more typical situation was one of complex health concerns, often presenting in minor and complex ways such that it was difficult to identify the major underlying pathologies. All our clinician respondents readily acknowledged the additional features of multi-morbidities and diverse symptoms which presented substantial diagnostic challenges.

Further, the concept of whole body pain was felt to be a specific problem which was particularly common in this population. This type of pain was considered clinically challenging because it was difficult to both identify the cause and treat it effectively. It

presents a largely intractable problem which dominates the clinical picture and impacts on clinical judgements even for those practitioners who were aware of this situation

*"They come and say 'I've got aches and pains all over. Pains in my knees, in my shoulders, in my back and I've also got it here in my chest'. And I don't think we're picking it up in the first place as well as not treating them with revascularisation.'" (GP)*

### **Obstacles to testing and treatment (Filter 2&3)**

When Pakistani women were referred for cardiology investigations, our findings suggested that a number of factors contributed to delays in diagnosis and therefore treatment decisions.

The women's life circumstances precluded them from effectively and independently navigating health services. All were first generation migrants, they spoke little English and, apart from one, had not been in paid employment. The majority lived in a deprived neighbourhood and survived on a low income. Five of the six were either widowed or separated and four were primarily supported by their children and dependent on them for negotiating access to the health services.

The clinicians were also aware of the ways in which the broader context of Pakistani women's lives negatively impact upon their ability to engage with the service and drew attention to the ways in which the current referral system fails to accommodate their needs.

Both primary care practitioners identified problems with non attendance for tests. Information management systems were one contributory factor. Similarity of names, name ordering, alternative spellings and lack of precision and consistency in reporting of personal details increase the potential for errors. These system errors

were not readily apparent and may only come to light subsequently, when primary care staff undertake checks and follow up non attendance.

Failure to attend for investigations contributes to delay of diagnosis. This delay could be further compounded by current policy which requires re-referral of those who did not attend. The impact of this was considered to fall disproportionately on these women and their health providers as the quote below illustrates;

*"You understand why the acute services need to say two strikes and you're out but for our patients it's a dead loss because there are so many places in the process where it fails..... it is just so much more complicated than if you live in [a wealthy neighbourhood] where you put it in your iphone and you turn up. It's not like that here so we phone up and say that they've missed it and they say you'll have to write a new referral letter....here you do it 3 or 4 times to get them [the women] there [the hospital] and there are endless complications along the way. It's just not straightforward." (GP)*

In addition to delays and non-attendance, when Pakistani women do attend for investigative tests, the experience may not be positive for them and is far from straightforward for the providers who are seeking to investigate their medical condition. The diagnostic challenges which occur in primary care continue along the pathway and into secondary care. At this stage of proceedings, when CHD is suspected, judgements are based on clinical assessment and test results. Problems were highlighted by our respondents with both of these elements. As the cardiologist explained, interpreting the test results can be particularly difficult in specific groups of people, especially women, and the diagnostic problems associated with a complex

and non specific clinical presentation experienced by the primary care practitioners are equally as problematic for the specialists;

*"...it is often hard to distinguish what their symptoms are due to - whether they are cardiac symptoms or the manifestation of a whole load of other things that we may not be able to get to the bottom of." (Consultant cardiologist)*

Specific problems were recognised with the investigative procedures and particularly the exercise test which requires the patient to stress their heart by walking on the treadmill under closely monitored supervision in order to determine how the heart responds to that stress.

From the women's perspectives, their inability to communicate with the health professionals made it difficult to understand the procedures they were required to go through as part of the diagnostic process and created a feeling of extreme vulnerability in them. One woman's account illustrated the problems that she experienced in relation to the treadmill test. She, like the majority of the respondents, had several serious illnesses and was unable to move, walk or undertake moderate activities without pain and stress. Her lack of understanding of the test impacted adversely on her ability to engage meaningfully with and complete the test.

*"I experienced that tightness of my heart in that test. I had diabetes, blood pressure, cholesterol, heart problems before that test. That tread mill test caused another mild angina." (Farida)*

From the clinicians' perspective, it was considered extremely challenging to support the women to undertake the test and achieve the levels of exercise required to produce a result, largely because of communication problems. The test commonly

induces a high degree of anxiety in patients because it may provoke symptoms and produce pain. Effective communication and a trusting relationship within which the nurse can 'push' the patient to a point where meaningful results can be achieved whilst simultaneously assessing and monitoring the patient to prevent the occurrence of adverse effects is critical as the nurse manager explained;

*"They're hanging on, they're scared of getting the pain, they've come because of chest pain, they're going through a third party to tell us they're getting pain, for us to make a decision on whether to stop the test. We need to push them as much as we can, but we need them to tell us when they can't do it anymore.... and if they're getting pain we need to see that reaction straightaway"*

The key to this was the nurse's ability to instil a sense of control in an anxious and fearful patient such that she felt able to cope with the situation and therefore more able to continue with the test. Clearly, effective two way communication was paramount in these circumstances but frequently lacking for Pakistani patients, as we discuss in more detail next.

#### **Communication and trust (Filters 2, 3 & 4)**

Communication was an overarching theme in both the women's and the clinicians' accounts although the emphasis differed between the two sets of accounts.

Whereas the clinicians' concerns were largely centred on the communication process and the accuracy of information in the clinical consultation, the women's accounts reflected wider concerns about the impact of poor communication on their ability to place their trust in the service and the providers.

From the clinicians' perspective, communicating effectively across language and cultural barriers was very challenging. Particular difficulties were identified in terms of

the way that pain, a major diagnostic indicator in CHD and therefore central to the consultation, was communicated. Diagnoses are reliant on detailed and nuanced descriptions of the characteristics of the pain; its location, duration and qualitative features, in order to interpret what it might signify. When patients articulate their experience of pain in qualitative terms which are not familiar to the practitioner, it makes it difficult to determine significance and interpret the pain accurately, a situation that is further complicated when operating across language barriers and through an interpreter. The following quote from the Nurse Practitioner provides insight into the frustrations that can arise for everyone in that situation

*"People have ways of describing things, and that can cause difficulties because they describe it in a way that I wouldn't describe it and so I ask them to describe it again and they tell you something different and then you ask them again and I think they get quite annoyed. And then you have to step back and explain, 'I really need to know more about this pain, What type? What does it feel like?'"*

All the clinicians discussed the complexities of working with interpreters and of conducting effective consultations via a third party. They identified particular challenges with the telephone interpreting service which is used extensively in primary and secondary care. One problem is a perceived reluctance and resistance by the women who they felt prefer to either manage on their own if they have some English or rely on family members as interpreters. One suggested reason was the loss of advocacy that comes from having an interpreter at the end of the telephone rather than in the room. This problem can be overcome if the speakerphone is used and the family member is included in the consultation, as the GP explained.



*"Quite a lot of people use a family member. A lot prefer family members over the phone and that's partly, that's because they want an advocate with them. And we say to them, 'Well, you can have both. You can have your family member with you and we'll use the phone'"*

However, conducting a consultation in this way is complex, takes additional time and requires training. Although all our clinicians had substantial experience of working with interpreting services, only one of them had received any training in this area.

The women's perspectives provided insight into the way that poor communication undermined their trust and confidence in service providers. Several of the women detailed accounts from their medical history where they felt that they had not been listened to, where they considered late diagnosis and inappropriate treatment had caused further medical problems and where they believed information had been deliberately withheld from them. These experiences have a cumulative effect, and create an environment of distrust within which the women make decisions about whether and how to engage with the health system and the advice of health professionals. Noor's story illustrates how her distrust and disempowerment led her to reject the offer of revascularisation.

Noor catalogued a series of medical procedures spanning eleven years that stemmed from a gynaecological condition that required surgery. She struggled to deal with the consequences of surgical complications in a health care system where she was not listened to, where she had difficulty making herself understood and where her ongoing problems were largely dismissed. Her subsequent experience of angiography was also problematic. Complications had occurred and been poorly explained which led her to believe that she was the victim of a conspiracy of silence

and to feel that '*doctors have messed up my life completely*'. Consequently, she had come to believe that medical interventions do more harm than good and had therefore rejected heart surgery;

Similarly, Nargees had rejected revascularisation because she could not contemplate the prospect of going through the procedure without adequate explanation, illustrating the extreme feelings of vulnerability that can result from lack of effective communication with providers;

*"My GP says that my heart arteries are blocked. I have been told that my heart operation will be done if required. I am really very scared of having an operation. I said to her that I don't want to go for the option of an operation...I get scared as soon as the door of operation theatre is closed and I don't understand the language. If I understand people then I feel relaxed and comfortable."*

## **Discussion**

Before discussing our findings and drawing conclusions it is important to acknowledge that this was a small scale, exploratory study. As such, it is possible that theoretical saturation was not achieved and that not all relevant issues were identified. This limits the generalisability of the findings to other settings. The respondents broadly reflected an age group with high prevalence of CHD , but in terms of ethnicity it is important to recognise the substantial heterogeneity that exists within the ethnic grouping 'Pakistani' and the range of responses to ethnic diversity within NHS organisations across England that could result in quite different patterns of care. Nevertheless, our findings chime with other recent accounts that have reported (i) 'atypical' presentation of heart disease among south Asian patients (Zaman et al. 2008, Teoh et al. 2007) (ii) low levels of awareness of symptoms of heart disease and delayed presentation by South Asians (Ben-Shlomo, Naqvi &

Baker 2008), (iii) significant distrust and experiences of ineffective communication among Pakistani users of health services (Mir & Sheikh 2010) and (iv) the ways in which older Pakistani women's healthcare experiences are commonly shaped by their vulnerable position within wider society (Ahmad & Walker 1997). The study adds to this existing body of knowledge by illustrating how these, and other factors, inter-relate to undermine the effective diagnosis and treatment of CHD in British Pakistani women.

Adopting a Pathways to Care Model enabled us to build up a picture of key factors that operate to impede patient progression. Although this Model has been usefully expanded to better understand the pathway prior to visiting the GP (Bower & Gilbody, 2005), the aims of our study were better served by the original format. Of particular value in this study is the generation of data from clinicians and women that related to the whole care pathway. Importantly, this approach has highlighted issues impacting at several points along the care pathway which therefore warrant a coordinated response, as well as issues that have relevance at particular stages. The approach also illustrates the ways in which individual factors interact with system characteristics to create obstacles. Furthermore, it throws into sharp relief how Pakistani women's trust and engagement with particular service settings and providers can be importantly shaped by prior experiences and encounters within the health system, regardless of their context, underscoring the importance of ensuring competent care and effective communication across the whole pathway. Three broad sets of findings are worth reiterating here to illustrate the above points.

Firstly, the testing and diagnosis themes indicate specific diagnostic difficulties associated with CHD in this group of women. Previous work has identified similar problems in relation to white working class patients (Tod et al. 2001). However a

number of factors compound the problem in relation to Pakistani women including their social and cultural circumstances, the substantial difficulties of working across language and the higher prevalence of multi-site musculoskeletal body pain (Allison et al. 2002). Cardiology investigations, particularly the exercise tests, also appear to present particular problems for this population of women. The Pakistani women have difficulty understanding and engaging with the test and the clinicians have difficulties in supporting them to complete the test. Non completion of tests and referral for more technologically demanding and costly procedures impacts on the woman and has resource implications for the service. These findings suggest the need for clinicians across the care pathway to share experiences and collaboratively develop approaches that address these problems. More effective dialogue with patients about signs and symptoms of disease that is informed by an understanding of the idioms of expression commonly used by this patient group offers one promising area for exploration. Additionally, interventions at community and primary care level to equip prospective patients with greater levels of confidence and understanding prior to referral for investigative tests.

Second, communication difficulties serve as filters (or, in effect, barriers) at all stages of the care pathway and contribute to loss of trust. The impact of poor or ineffective communication on the woman and her disease experience can be profound and far-reaching. The complexity of the consultations and the nature of cardiology investigations, which commonly preclude the presence of family members, place a heavy reliance on the interpreting service. Conducting an effective consultation via an interpreter is difficult. It turns a dyadic interaction into a triad, adds to the complexity of the social situation and produces operational and technical challenges (Greenhalgh, Robb & Scambler 2006) which are further complicated when the

interpreter is at the end of a telephone line. All our clinicians highlighted this issue as one that impacts significantly on care provision. It is a matter of concern that only one of them had received appropriate training. Training staff to work with interpreters is essential because it increases effectiveness of consultations (Gerrish 2001) and contributes to optimal use of this service. Furthermore, it would seem helpful for clinicians across the care pathway to come together to share the insights and approaches that they have developed through caring for these women.

Third, the wider socio-cultural and economic context shaping the life circumstances of many older British Pakistani women's lives makes them highly vulnerable and dependent upon other people, factors that importantly shape their experiences as users of the health service. This inherent vulnerability is exacerbated where a healthcare system does not accommodate for these contextual factors. In particular, fixed appointment systems can disadvantage patients who have limited autonomy and complex family demands, and name recording difficulties in clinical record systems can militate against care coordination and effective follow-up. The clinicians we spoke to were well aware of these system inadequacies, which highlights the importance of ensuring an appropriate degree of sensitivity and responsiveness to the needs of individuals who are at high risk of being excluded.

## **Conclusion**

Pakistani women's journey through the CHD care pathway is impeded by a range of factors which serve as filters, and influence the likelihood that they will arrive at the correct treatment endpoint. The framework provided by the Pathways to Care Model has enabled the identification of some significant limiting factors from the narrative that are associated with life circumstances, communication, delayed diagnosis and the investigative procedures employed. This approach offers some insight into the

causes of the previously observed attenuation in the progress of women of all ethnicities along the cardiac diagnosis and treatment pathway.

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