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# Exploring the role of physician communication about adjuvant endocrine therapy among breast cancer patients on active treatment: a qualitative analysis

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# Abstract

**Purpose**—To better understand how physicians communicate with breast cancer patients about adjuvant endocrine therapy (AET), we explored, from the breast cancer patient's perspective, dimensions of the patient-provider communication among women who were on active AET treatment.

**Methods**—Qualitative methods using semi-structured in-depth interviews were conducted with breast cancer patients (n = 22) who filled a prescription for AET in the previous 12 months. Interview questions aimed to elicit experiences with AET. We reviewed and coded interview transcripts using qualitative principles of inductive reasoning to identify concepts and themes from interview data.

**Results**—We grouped emergent themes into four major functions of physician-patient communication: (1) information exchange, (2) decision-making to take and continue AET, (3) enabling patient self-management and monitoring potential side effects, and (4) emotional support. Physicians exchanged information with patients in a way that they understood and enhanced patient's health literacy regarding the benefits and knowledge of AET. Physicians empowered patients to make decisions about their care. Patients expressed trust and confidence in their

Compliance with ethical standards

**Ethical approval** All procedures performed in this study involving human participants were in accordance with ethical standards of the institutional research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. **Conflict of interest** The authors declare that they have no conflicts of interest.

physician which helped them seek care when needed. Patients reported a high degree of selfefficacy to self-manage AET and were continuing treatment despite potential side effects.

**Conclusions**—The results from our study suggest that women's interactions and communication with their physician may be an important factor that contributes to the continued use of AET. Physicians who can communicate information about AET treatment benefits, purpose, and expectations in a way that patients can understand is a critical aspect of care that needs to be further studied.

### Keywords

Adjuvant endocrine therapy; Qualitative study; Breast cancer; Survivors; Physician-patient communication

### Introduction

Estrogen receptor-positive breast cancer is diagnosed in two thirds of breast cancer cases in the USA [2, 10]. Treatment with adjuvant endocrine therapy (AET) is recommended for 5 years for women with ER+ breast cancer [27]. AET includes tamoxifen and the aromatase inhibitors exemestane, letrozole, and anastrozole. Treatment with tamoxifen is recommended for pre-menopausal women, and aromatase inhibitors are recommended for postmenopausal women [27]. Women treated with AET experience improved disease-free survival [8, 20]. However, despite the effectiveness of AET to improve survival and decrease cancer recurrence, adherence rates to recommended treatment remain low. It is estimated that between 73 and 88 % of breast cancer patients are adherent to medication in the first year, and up to 50 % of patients become non-adherent within 4–5 years of initiating treatment [6, 30, 35].

Factors related to the continued use of AET have focused predominately on the demographic and disease-specific characteristics related to breast cancer treatment [3, 35]. The health beliefs of breast cancer survivors are also shown to be important factors that contribute to women taking AET [1]. However, interpersonal interactions may also influence the use of AET.

Physicians play an important role in the on-going care of breast cancer survivors, particularly women who are actively taking AET. The role of the physician can both positively and negatively affect medication adherence [24]. Theory suggests that physician-patient communication functions such as information exchange, responding to emotions, making decisions about the initiation and continuation of treatment, and enabling self-management can have direct and indirect effects on health outcomes [36]. Information exchange refers to communication about aspects of care and can influence the use of AET if the physician successfully communicates information about the risks of treatment and clinical evidence on the effectiveness in a way that is understood by patients [18, 36]. When medical decisions to undergo and continue a treatment regimen are a shared responsibility of the patient and physician, they come to an agreement based on the available clinical evidence and what is feasible to implement [14]. Physicians can also encourage patients to manage important aspects of their illness such as seeking appropriate care, coping with

treatment side effects, and finding health-related information [21, 29]. Finally, physicians who can help patients manage emotions and uncertainty about their illness can reduce distress and help the patient to cope with the disease, build self-confidence, and a sense of worth [32]. Generally, these communication functions can lead to greater patient trust in the physician, enhanced health literacy, and a greater willingness to follow through with treatment [7, 15, 24, 36].

These communication functions stress the potential importance of the role that physicians have to interact and communicate with breast cancer patients about AET. Therefore, the objective of this study is to explore, from the patient's perspective, how physicians communicate with them about all aspects of AET treatment.

### Methods

### Study design

We conducted semi-structured in-depth interviews with breast cancer survivors in order to understand their beliefs, experiences, and perspectives regarding the complex issue of taking AET [11]. By using this approach, women were encouraged to talk openly about their experiences with AET in a conversational manner yet we were able to systematically collect similar information about each participant's experience [16]. The study was approved by the University of Washington's Institutional Review Board.

#### Participant recruitment

Eligible women were defined as breast cancer patients who filled at least one prescription for tamoxifen, exemestane, anastrozole, or letrozole in the last 12 months. Women were recruited from two geographic regions in the USA between September 2014 and April 2015. In Los Angeles, California, women were recruited with informational flyers sent to email list serves of breast cancer support/survivorship groups, and placed in oncologist's offices. Flyers contained the purpose of the study, eligibility criteria, and staff contact information. In Houston, Texas, women were recruited from breast cancer survivorship support groups that were identified from an Internet search. Study staff contacted the groups, presented the purpose of the study, handed out flyers, and answered questions during a monthly meeting.

### **Data collection**

Potential participants contacted the first author and were screened over the telephone to ensure that they met study inclusion criteria. We then scheduled a face-to-face interview at a time and place that the participant felt most comfortable being interviewed. The interviewer obtained a signed informed consent from the participant prior to the interview. The majority of the interviews took place in study rooms at public libraries, and at the participant's workplace. The interview ended when the interviewer asked all of the open-ended questions from the in-depth interview guide. Each interview lasted between 35 and 60 min. Women were given a \$25 gift card at the conclusion of the interview. Case summaries were written after each interview; each described the interview setting, general impressions, and/or salient themes that emerged from each interview. All interviews were conducted in English by the

first author until the study team decided that they reached saturation in which no new data emerged from the interviews.

### In-depth interview guide

Interviews were designed to allow an open conversation about each woman's experiences with AET. The semi-structured interview guide consisted of 30 open-ended questions that were developed to understand how social, cultural, and health care factors influence women's experiences with AET (Appendix). Specifically, we were interested in how these factors influenced participants' barriers and benefits to use AET, and their perceptions of the susceptibility and severity of cancer recurrence. Interview topics included the history of breast cancer diagnosis and treatment, experiences with side effects from the initial breast cancer treatment, relationship with physicians during the initial treatment, treatment decision-making, views about cancer survivorship, and experiences and side effects of subsequent hormonal therapy. In this paper, we focused our analysis on the participant's description of their relationship and interactions with the physician. Demographic information including place of birth, age, income, household composition, marital status, and education were recorded at the end of each interview.

### Analysis

The interviews were recorded using a digital audio device, professionally transcribed verbatim, and were checked for accuracy and to distinguish inaudible words by the interviewee. Three interviews were inaudible because of the recording quality and could not be transcribed.

The transcripts were uploaded into Atlas.ti, version 7, a qualitative data analysis software program (Atlas.ti, Berlin, Germany). An initial list of codes were developed by the research team using an a priori approach, based on the interview questions and overall study goals [5, 22, 25, 26]. We used an inductive, constant comparison approach to identify additional concepts and themes from the interview data. The first four interview transcripts were coded line by line by two coders to check for reliability and familiarity with codes. Each coder then separately coded six or seven transcripts. The final two interview transcripts were double-coded to check for consistency in coding. We met weekly, in an iterative process, to refine the codebook by adding, removing, and revising codes to capture emerging themes. The study team (AF, SH, IO, BT) met regularly to discuss themes from the data, to determine linkages across participants and thematic categories, and to corroborate on exemplary quotes to represent each theme. For the purpose of this study, the emergent themes were explored and limited to instances when the women described the interactions with, or thoughts of, their physician.

### Results

We interviewed 22 women. The interviewed women were predominately white (59.1 %); however, African American women accounted for over one-quarter of the participants (27.3 %) (Table 1). Fifty-three percent of the women were under the age of 55 years old. The majority (63.6 %) of the women had a household income of \$50,000 or more, lived with one

or more people (59.1 %), and nearly three-quarters of the women (72.7 %) had at least a bachelor's degree. Women reported currently taking either aromatase inhibitors (exemestane or anastrozole) (50 %), or tamoxifen (50 %). Most of the participants (72.7 %) were interviewed in Los Angeles, CA.

Based on the emergent themes from the interviews, we observed that they could be grouped into four functions of physician-patient communication: (1) information exchange, (2) decision-making, (3) patient self-management, and (4) response to emotions and uncertainty which are similar to the theoretical framework described by Street and Epstein (Table 2) [36].

### Providers facilitated the exchange of information about AET

Women in the study described how their physician talked to them when deciding to take AET and to continue treatment. The women reported that their physician talked to them about the purpose, benefits, and treatment duration of AET medication. All of the women were able to articulate the way in which the drugs worked and stated that their physician described their cancer as "estrogen-fed," "slow growing and extremely hormonally positive," and "growing because of the hormones." The women reported that their physician said that they "needed to starve the cancer of estrogen to prevent it from growing," and to "slow the cells down." The women understood from their physician that using AET would help "reduce the [cancer] recurrence rate" and to "contain the estrogen." Almost all women used phrases such as "clinical studies with the latest information," "published studies," or "new research" to describe how physicians talked to them about the benefits of AET to reduce cancer recurrence. One woman reported that their physicians called AET the "5-year pill," while other women said that they would have to take "one pill per day for five years". Some women even understood that they may have to be on AET treatment for up to 10 years because of "new research."

#### Providers empowered women to make care decisions

The women understood that the decision to take and continue AET was ultimately up to them and was based on a discussion with their physician and their physician's recommendation. Women were often deciding to take AET based on trade-offs with the risk of a breast cancer recurrence and side effects from treatment. One woman explained:

"I need my questions answered in whatever way that she [the oncologist] can statistically, because she can't say personally what's going to happen to me. And then I'm going to have to decide which [AET treatment] I want."

The recommendation to take AET was often a discussion about the benefits and potential side effects of treatment described in the previous section. As another woman described:

"I saw her a month or two ago and I was discussing it and basically, I don't make instant decisions, and she's telling me, well this is this. This is that. So, what do you want to do?"

The women ultimately made the decision to take and continue AET but a majority of them knew that it was a choice which was influenced by communication with their physician and the physician's recommendation as one woman noted:

"It basically was brought on by my oncologist...well of course, you don't have to take it if you don't want to" ... "I reached the conclusion [to take AET] with the doctor's help, of course".

### Providers enabled patients to self-manage treatment and monitor potential side effects from AET

Many women noted that physicians aided in the self-management of their disease. Women were actively engaged in managing their own care by asking questions during routine follow-up care where physicians addressed concerns and treatment side effects or potential side effects of AET. Women either had experienced side effects such as hot flashes during AET treatment or were still experiencing them. The severity and frequency of hot flashes varied across the women; however, many women noted that the side effects dissipated the longer that they were on the AET medication.

An emergent theme to help with the side effects and/or potential for future side effects was that women knew exactly when they had their next routine visit with the physician to manage their care. Many women described "I see my oncologist every 90 days" or "every 3 months." When asked what they talk about during these visits, one woman said:

"We're primarily making sure that the hormone levels have dropped enough or dropped or risen, depending on what they're looking for. So, it's for blood work and just to monitor side effects from the tamoxifen."

Women who were experiencing or had experienced side effects reported that physicians helped them manage the side effects of AET. Women managed the side effects of AET that involved physicians recommending or prescribing both medicinal and non-medicinal strategies. Women also expressed that they felt comfortable calling or making appointments with physicians as needed. Active management of side effects or knowing what to do when they experienced side effects seemed to increase the woman's self-efficacy to continue on AET. For example, when one woman was asked how confident she was that she would be able to continue with treatment for 5 years, she responded:

"It should be fine, I mean, if I start having any problems then I'll let her [oncologist] know and see if we can't find something to help."

All women in the study, at one point during AET treatment, experienced hot flashes. One woman said that:

"They [doctors] recommended I take it [AET] in the evening so that I'm not dealing with being hot during the day. So it was more just controlling when I was going to have them because that's a common side effect with it."

Another woman indicated that her physician prescribed an antidepressant to help with hot flashes:

"It's an antidepressant... But, for whatever reason, that medicine does decrease hot flashes."

And another woman indicated that:

"My oncologist recommended to try to take over-the-counter supplement first, if it does not work, then she would prescribe me something."

We found that patients were actively engaged in follow-up care because physicians fostered relationships where women felt comfortable talking to the physician about any issues related to AET treatment or cancer recurrence.

"Some women can't take [Arimidex], some women can. And that's why it's important to stay on with your oncologist, because you can tell them the symptoms that you have...in order to help yourself, you have to talk to your doctor and that's what I'm doing now."

# Providers helped manage patient's emotions and the uncertainty of care by treating patients personably and being well regarded in the field

Many women felt worried and uncertain about whether their cancer would return. The women wanted assurance that they were doing everything that they could to keep the cancer from coming back. Physicians were able to help manage these emotions because they provided care that was personable and made the women feel respected. When describing their care, almost all participants focused on the personality traits of their physician. Common descriptions of their physicians were "he was nice", "he's very positive but he's realistic", "the doctor was very present and caring", and "very respectful and not condescending". These personality characteristics seemed to help patients emotionally cope with the diagnosis of breast cancer and helped set the tone for effective communication between them and their physician.

In general, we found that the communication with their physician made women to feel respected and cared for. One participant noted that:

"He [oncologist] knew me by my name, my face. When I came in, it was like they treated you like you were a person and not just cattle coming through". "He used to call me his most delicate patient."

We found that women often described their doctors as "very well respected and prominent in the field" and as someone who "does a lot of research with tests", and is someone that is a "respectable person". Women placed a lot of value on the level of expertise of their physician, and it was evident that they trusted that their physician provided the best care. This confidence helped the women deal with the uncertainty that the breast cancer could come back and motivated them to continue AET treatment. When asked why she was continuing with treatment despite all of the side effects that she was experiencing, one woman stated:

"Why am I continuing with it? I think a lot of it has to do with kind of the confidence in my doctor...she is the doctor and she knows what the clinical trials are showing."

### **Discussion and conclusion**

Our study described the interactions between physicians and patients with ER+ breast cancer currently using AET. The interviews showed that physician-patient communication plays an important role in both the initiation and the long-term continued use of AET for women with breast cancer. Specifically, we found that information exchange, shared decision-making, emotional support, and patient self-management of care were aspects that encouraged the use and continuation of AET. Despite the concerns about potential future side effects of AET, many patients expressed reassurance that their provider would help them manage these problems if they occurred so they would not need to discontinue treatment. For women who experienced hot flashes, they described a willingness to continue taking AET because of the trust and confidence they have in their physicians, and the help they received from their physicians in managing discomfort of hot flashes.

One goal of health information exchange is for the physician to offer a clear understanding of what to do to improve one's health, why it is being done, and precisely, how to do it [33]. Information exchange that focuses on understanding the medical issues of a patient's condition is most successful when patients understand the information explained to them by their physician [18]. Successful health information exchange and enhanced health literacy can be exemplified when the patients can "teach back," or repeat the information provided by their physician [33]. We found that every woman in the study had a high degree of health literacy regarding AET treatment by the way they described the information given to them by their physician. Health literacy regarding the disease or treatment efficacy has been shown to improve treatment adherence [28]. Evidence suggests that patients' strong belief in the necessity of a treatment also improves adherence to medication [17, 19].

Elwyn et al. describe a shared decision-making model for clinical practice in which the physician describes the choices and helps patients explore preferences and make decisions [13]. In our study, participants understood that the decision to take and continue AET treatment was a choice for which they took responsibility, using the information and recommendations that their physician provided. Physicians seemed to help women make a decision to initiate and continue AET treatment by exploring patient preferences while presenting the benefits of AET to reduce cancer recurrence and describing potential side effects and how to manage them if they developed. When patients are part of the decision-making process by actively participating in the encounter, regardless of who assumes responsibility for the final decision, they often have less regret about the decision and anxiety and experience better health [23, 38]. Treatment decision-making that involves patient input is associated with higher adherence to antidepressants, asthma-controller medications, and diabetes medication [4, 39].

Physicians can help patients manage the emotional aspects of their treatment experience by interacting with them in a way that builds their trust in the care that they are receiving [36]. Physician behaviors that build trust generally fall into categories of competency, communication, caring, honesty, and partnering [37]. It is no surprise that our findings about how women described their interactions with their physician by emphasizing caring personality traits and reputation led to greater trust in their physician. Physician trust has

been shown to improve adherence to antihypertensive medication and may also be important with the use of AET medication [12, 31].

Patient self-management is aimed at enabling patients to cope with treatment effects and seek appropriate care [36]. Physicians can encourage self-management by providing guidance and advice on better self-care [36]. Women often experience side effects such as hot flashes, joint aches, and sleep disturbances while taking tamoxifen and the aromatase inhibitors [9, 34]. Side effects are associated with lower adherence and early discontinuation of AET treatment [9, 34]. In our study, physicians were actively involved in the management of breast cancer treatment which eased women's fear of potential side effects from AET and women felt empowered to manage their own treatment. Physicians who encourage self-management empower patients to have a sense of control, or self-efficacy, over any health issues that may arise from treatment [36]. A patient with lower perceived patient self-efficacy with regard to their ability to regularly take medication is associated with lower adherence to AET [40]. Therefore, physicians who enable patient self-management to cope with treatment effects of AET treatment may improve women's self-efficacy to continue treatment and lead to higher medication adherence.

All of the women in our study were actively taking AET. Eligibility criteria included women who had filled a prescription for AET medication in the past 12 months which may explain why women were actively taking medication. A longer time period for prescription refills may yield more women who discontinue taking AET. The women in our study were highly educated and had an income at or above the US median household income; therefore, we may not have identified aspects of the patient-physician interaction that serve as barriers to AET use, such as the cost of AET medication. The results from our study, however, provide insight into the physician-patient interactions that occur among women actively taking AET. We identified important functions of physician communication that could be addressed in order to improve the use of AET. Our findings are supported by a theoretical framework that demonstrates that these functions operate to improve adherence to medications and health outcomes [36]. Physicians are just one of the interpersonal factors who might influence a woman's decisions about AET use. Future research should explore the influence of the social and cultural environment and how these relationships support the use of AET.

# Conclusions

Our study highlights that providers acknowledged that side effects such as hot flashes are likely and that there are ways of managing the discomfort of them when and if they arise, and that providers highlighted to women the benefit of taking AET so that women felt knowledgeable and empowered to make personal decisions to initiate and continue AET. Depending on the woman's experience with hot flashes, the decision to take and continue AET treatment was centered on whether the reduced risk of recurrence was personally worth the discomfort. The way in which physicians communicated with these women about AET, particularly oncologists, played an important role. At the very least, physicians who provide care to women currently taking AET treatment should assess patients' understanding of the way that the drugs work and the benefits of AET treatment, as well as actively engage them in follow-up care for treatment side effects. Women may be more likely to continue AET

treatment if physicians can communicate these key pieces of information to them in a way that they understand. These physician-patient communication functions could improve trust, health literacy, and self-efficacy of women taking AET. Future research should examine the physician-patient interactions of patients who discontinue or never initiate AET treatment and whether or not interactions differ by race/ethnicity.

Physicians play an integral role supporting the interpersonal relationship between them and breast cancer patients. Effective physician communication can support the long-term continued use of AET. Adherence to AET could be enhanced by understanding and addressing how physicians interact with patients to exchange information about the effectiveness of AET treatment, foster the decision to take AET, encourage self-management of treatment, and respond to patients' emotions regarding their care and fear of recurrence.

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# Appendix: Adherence to Adjuvant Endocrine Therapy among Breast Cancer Survivors: Qualitative Instrument

### Cancer diagnosis and initial treatment experience

- 1 Will you describe the type of cancer you have?
- 2 What do you think caused your breast cancer?
- **3** Where did you have your treatment for breast cancer?
- 4 What type of medical treatment did you have for your breast cancer?
- 5 What were the options that your doctor gave you for your treatment?
- 6 Alongside the medical care your doctor gave you, did you use any other traditional medicine, such as acupuncture, herbs, etc. to treat your cancer?
- 7 Can you describe for me how your doctors and nurses treat you?
- 8 Where did you find emotional support or comfort for your emotions during the time you were going through treatment?
- **9** Is there anything that would have helped you to better deal with your cancer diagnosis and treatment?

## Cancer survivorship and long-term adjuvant treatment

After receiving treatment, some people experience being very tired, have pain, or trouble with their memory, do you have any of these?

# Adjuvant hormonal therapy

10	Are you c	currently going to t	he doctors f	for your	breast can	cer?
				-	_	

- 11 Are you currently taking any medication for your breast cancer? [Tamoxifen, anastrozole (arimidex), exemestane, letrozole]
- I. How often do you take these pills?
- **II.** What, if any, side-effects do you have from these treatment(s)?
- **III.** Has your doctor ever told you how long you should be taking these medications?
- **IV.** How confident do you feel that you will be able to continue with the treatment?
- 12 What did your doctor tell you were the benefits of taking the medication?
- 13 What do you believe are the benefits of taking the medication?
- 14 Why are you continuing with your treatment?
- 15 How difficult is it for you to regularly take medication for your breast cancer?
- 16 What made you decide to receive additional treatment?
- 17 What has your doctor told you that you should do to keep your cancer from coming back?
- **18** How would you feel if your doctor prescribed for you to take a pill once a day for up to 5 years to help your cancer from coming back?
- 19 Has your doctor told you how often you should see him/her or another doctor?
- **20** What would be the most challenging thing to keep you from taking the medication?
- 21 Do you ever think about the cancer coming back?
- 22 Is there anything else that you would like to talk about with your doctor regarding your cancer?
- 23 People who have had cancer often call themselves "cancer survivors". Do you see yourself as a cancer survivor?

# Sociodemographic

- 24 Where were you born?
- 25 How many years have you lived in this country?

	years
Are y	ou:
a.	married or living as married
b.	single
c.	divorced
d.	widower
What	is your household composition?
What	is the highest level of education you completed?
a.	no education or kindergarten
b.	elementary school (1-6)
c.	middle school
d.	high school diploma or equivalent (GED)
e.	some college, Associate's degree, Vocational or Technical College
f.	Bachelor's degree
g.	Master's or doctoral degree
Please falls.	e tell me into which category your total household income for one year
a.	Less than \$15,000
b.	\$15,000 to less than \$20,000
c.	\$20,000 to less than \$25,000
d.	\$25,000 to less than \$30,000
e.	\$30,000 to less than \$35,000
f.	\$35,000 to less than \$40,000
g.	\$40,000 to less than \$45,000
h.	\$45,000 to less than \$50,000
i.	\$50.000 or more

### Table 1

# Sample characteristics (n = 22)

Chanastanistia	
Characteristic	n (%)
Age, years	
<45	5 (22.7)
45–55	7 (31.8)
55–65	6 (27.3)
>65	4 (18.2)
Race/ethnicity	
White	13 (59.1)
African American	6 (27.3)
Asian	2 (9.1)
Hispanic	1 (4.5)
Adjuvant Endocrine Therapy	
Aromatase Inhibitor	11 (50.0)
Tamoxifen	11 (50.0)
Income	
Less than \$15,000	2 (9.1)
\$15,000-\$50,000	6 (27.3)
\$50,000 or more	14 (63.6)
Household composition	
Alone	9 (40.9)
1	6 (27.3)
2 or more	7 (31.8)
Marital status	
Single	6 (27.3)
Married	10 (45.5)
Divorced	4 (18.2)
Widowed	1 (4.5)
Geographic region	
Houston	6 (27.3)
Los Angeles	16 (72.7)
Educational attainment	
High school or lower	1 (4.5)
Some college, technical school	5 (22.7)
Bachelor degree	10 (45.5)
Master degree	5 (22.7)
Doctorate degree	1 (4.5)

### Table 2

Themes and subthemes pertaining to patient report of their physician's communication to take adjuvant endocrine therapy treatment

Emergent themes	Subthemes
1. Information exchange between physicians and patients about AET treatment	Benefits of AET citing clinical trials Description of the way AET works AET treatment duration and expectations
2. Decision-making to take and continue AET treatment	Physician recommendation AET treatment is an option
3. Enabling patient self-management and monitoring potential side effects	Physicians actively involved in the management of side effects of treatment Physicians enable patients to cope with potential side effects by seeking treatment and/or with medicinal or non-medicinal strategies.
4. Emotional support	Physician personality traits Professional expertise Trust and confidence in physician's care