





RESEARCH ARTICLE

Women's coping strategies during the first three months of adjuvant endocrine therapy for breast cancer

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Abstract

Aim: The aim was to explore stressful events, experienced problems and used coping strategies during the first three months of undergoing ET.

Design: This study used a mixed method design.

Methods: A consecutive sample of 39 women newly diagnosed with breast cancer were included at the start of their adjuvant endocrine therapy. A daily coping assessment was used to create daily reports about stressful events or experienced problems and coping strategies.

Results: The most frequently reported *physical problems* were *sleeping difficulties*. *Anxiety* was the most reported *emotional problem*. Patients used both emotion- and problem-focused coping, and *sleeping difficulties* were coped by *relaxing*, and *anxiety* was coped by *thinking about something else*.

Conclusions: Patients experienced a variety of stressful events or problems during the first three months of endocrine therapy. They also used several coping strategies to endure the treatment.

KEYWORDS

breast cancer, coping strategies, endocrine treatment, experienced problems, oncological treatment, patient-reported experiences, stressful events

1 | INTRODUCTION

Receiving a breast cancer diagnosis is accompanied by emotional responses to both the diagnosis and the treatment, and women must adapt their coping strategies to handle this stress (Matthews, Grunfeld, & Turner, 2017). For women diagnosed with hormone-receptor-positive breast cancer, endocrine therapy (ET), that is tamoxifen (TAM) or aromatase inhibitors (AI) is recommended for at least five years, to reduce recurrence and rates of mortality (Davies,

Godwin, & Gray, 2011). Patients may experience diverse side effects related to their specific treatment (Laroche, Perrot, & Medkour, 2017; Moon, Hunter, Moss-Morris, & Hughes, 2017), and difficulties in managing these side effects have been identified as obstacles for treatment adherence (Bluethmann et al., 2017).

Coping strategies are individual management acts to cope with illness (Lazarus & Stress, 1984). Furthermore, the timing of the event and the sense of anticipation of the event affects how the patient appraises a potentially stressful situation (Lazarus & Stress, 1984).

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Discontinuation of ET occurs most frequently during the first three months of treatment, indicating that this period may be very stressful (Fontein, Nortier, & Liefers, 2012). Thus, research should examine several consecutive days after starting ET to understand how treatment can create stressful events and experienced problems over time (Zhu, Cohen, Rosenzweig, & Bender, 2018).

The aim of this study was to explore stressful events, experienced problems and used coping strategies during the first three months of undergoing ET. The following research questions were posed:

1. What type of everyday stressful events or experienced problems do patients prescribed with ET as a treatment for breast cancer experience during the first three months of treatment?
2. What singular stressful event or experienced problem was reported most frequently during the first, second and third months?
3. How disruptive are these stressful events or experienced problems from patients' perspectives?
4. To what degree do patients expect stressful events or experienced problems?
5. What coping strategies were used in response to these events or problems?

2 | METHODS

A mixed-methods (qualitative and quantitative) design (Creswell & Creswell, 2017) was used to provide a comprehensive analysis of the research questions.

2.1 | Sample and setting

This study was conducted in a surgical outpatient care unit at a university hospital in Sweden between February–December 2017. Inclusion criteria for patients were to be diagnosed with hormone-receptor-positive breast cancer and about to start ET (i.e. TAM or AI) after breast cancer surgery. Radiation as a concomitant treatment was permitted, but patients receiving neoadjuvant or adjuvant chemotherapy were excluded. Potential patients were identified at their first visit at the outpatient care unit, approximately one month after receiving breast cancer surgery.

2.2 | Data collection

The Daily Coping Assessment (DCA) was used because of its use of writing—encouraging patients to write in their own words their personal experienced stressful events or problems (Stone & Neale, 1984). The rest of the DCA contain pre-defined sections.

The DCA contains four sections:

1. *The most stressful event or experienced problem*—a question prompting respondents to describe the most stressful event

TABLE 1 Sociodemographic characteristics of the participants

Variable	(n = 39) n(%)
Demographic data	
Age, median (range)	63 years (44–90)
Married/In a relationship	29 (74)
Single/Divorced/Widowed	9 (23)
University/Graduate degree	20 (51)
Elementary school and/or High school	19 (49)
Employment, full or part time	22 (56)
Retirement	17 (44)
Swedish born	34 (87)
Treatment	
RT	29 (74)
TAM	28 (72)
AI	11 (28)
Terminated ET	1 (2)

Abbreviations: AI, aromatase inhibitor; ET, endocrine treatment; RT, radiotherapy; TAM, tamoxifen.

- or experienced problem that specific day and whether it is related to their treatment, using their own words.
2. *Distressed by the event*—a question to assess the distress caused by the stressful event or experienced problem. Levels range from one to seven.
3. *Reaction to the stressful event/problem*—a section including two questions concerning reactions to the stressful event or experienced problem. This assesses levels of expectation of the reported stressful event or problem.
4. *Strategies of coping*—a section including nine categories of coping strategies. The pre-determined coping strategies described in the diary included *to think about something else, to look at the problem in a different way, to do something about it, to express emotions (catharsis), to accept the problem, to get support from others, to relax and to seek spiritual support and other ways of coping*. Patients reported whether they used the strategy as a means of coping with what they reported as the most stressful event or experienced problem for that day.

The Swedish version of the DCA was translated by Wasteson and colleagues (Wasteson, Nordin, Hoffman, Glimelius, & Sjoden, 2002).

2.3 | Procedure

A consecutive sample of 53 female patients was screened for inclusion by the first author; consequently, 47 patients initially agreed to participate and provided written informed consent. Eight patients withdrew from the study before starting to write any diary entries. A final cohort of 39 women was included in the trial (Table 1). After patients provided consent, they were given the diary for the first month with oral instructions to use the diary to describe stressful events and experienced problems in relation

TABLE 2 Categories, subcategories, quotes

Categories and subcategories	Quotes
Physical problems	
Sleeping difficulties	Wakes up in the middle of the night (around 3 a.m.), sweating. Unable to fall back into sleep. Tired all day [p20] Another sleepless night, ache in the armpit [p26] Tired because I have sleeping problems [p31] Tired in a strange way [p39] It seems like I get tired from the medicine Tamoxifen Mylan [p4]
Pain, cramp, stiffness	Cramps in my leg this night [p17] Headaches [p29] Dizziness [p39] One hour after taking my pill I felt heavy dizziness for one to two hours... [p32]
Digestive organs symptoms	Diarrhea, have contacted Sahlgrenska, will change treatment against breast cancer [p29] Feeling nauseas a half hour after taking my pill in the morning [p39] Flatulence. It didn't happen instant, I feel my stomach hum, gas filled intestines for a couple of weeks now. But it gets more and more bothering. It feels like diarrhea all the time. [p23] Thirst, obstipation [p17]
Lower abdomen and genital symptoms	Feeling irritated and dry in the abdomen [p19] Swaying feeling "down there" [p20]
Infection	Have got antibiotics due to infection in the breast [p16] The breast is still red, swollen and tender [p26]
Hot flashes	Enormous sweets this night - interfered with the sleep [p3] Hot flashes at night, interfered sleep [p16] Hot flashes, wake up at night [p32]
Emotional problems	
Anxiety	Felt a great grief because of my situation. Cried. Heavy day [p13] Cancer anxiety [p28] Found a bump in the armpit... worried because of the bump in the armpit [p31] Feeling low, can't understand why. I'm just sad [p39]
Irritation	Feeling irritable, grinding on my husband about nothing [p20] Mood swings, angry [p33] Irritated [p12]
Pre-knowledge about ET	Starting treatment with Tamoxifen today. Feeling hesitation due to many eventual side effects (leaflets, FASS) [p14] Thinking all the time about that I should prepare for having to take a pill every day for 5 years. Menopause = sweating, becoming a part-time- bitch [p24]

to starting ET for 90 consecutive days. After two to three weeks, the diary for the second month was sent to patients with a complementary letter, the first author's contact information and a prepaid envelope. The third diary was sent after five to six weeks, with the same letter.

Among participants, 38% (15/39) withdrew from the study, including patients who actively withdrew their participation and patients who returned diaries with no written text. This resulted in 35 patients who returned their first diaries with described stressful events or experienced problems in relation to ET, 29 patients who returned their second diaries and 24 patients who returned their third dairies. We had an overall 84% reporting rate which led to 2,224 total days reported in this study. Not all patients experienced problems, so there was a selection of the reported stressful events

or experienced problems as follows. The diary reports was divided as related to ET, if the reported events were known to be side effects to ET (Zhu et al., (2018)), or not related to ET, if participants reported *no problems* or *life issues*. As the aim of this study was to explore the stressful events or experienced problems related to ET, the non-related results were excluded.

2.4 | Data analyses

2.4.1 | Qualitative analysis

Qualitative content analysis was used to search for patterns in the text and was guided by the first research question (Krippendorff,

TABLE 3 Reported Stressful Events, the Four Parts of the Diaries; Categories, Subcategories, Levels of Distress, Expectation and Level of Control

Categories	Subcategories	First month					Second month	
		<i>n</i> = 35; <i>n</i> (%)	Frequency	Distress ^a	Level of expectation ^a	Level of control ^a	<i>n</i> = 29; <i>n</i> (%)	Frequency
Physical problems		33 (94)	315	3.75 ± 1.67	2.67 ± 1.19	2.44 ± 1.07	24 (83)	308
	Sleeping difficulties	24 (68)	91	3.79 ± 2.07	2.56 ± 1.35	2.31 ± 1.22	18 (62)	92
	Pain, cramps, stiffness	24 (68)	78	3.94 ± 2.14	2.46 ± 1.31	2.54 ± 1.32	15 (52)	83
	Digestive organs symptoms	12 (34)	28	3.16 ± 1.47	2.47 ± 1.06	2.69 ± 1.15	8 (28)	30
	Lower abdomen and genital organs symptoms	2 (6)	5	3 ± 0.66	2.5 ± 0.56	2.33 ± 0.54	2 (7)	2
	Infection	5 (14)	12	4.58 ± 1.40	1.92 ± 0.62	2.42 ± 0.76	3 (10)	9
	Hot flashes	12 (34)	101	4.28 ± 2.08	3.14 ± 1.51	2.77 ± 1.29	12 (33)	92
Emotional Problems		12 (33)	65	4.51 ± 2.21	2.36 ± 1.10	2.26 ± 1.03	16 (55)	72
	Anxiety	10 (29)	51	4.11 ± 1.87	2.47 ± 1.05	1.99 ± 0.87	14 (48)	50
	Irritation	3 (9)	6	4.08 ± 1.09	2.83 ± 0.76	2.33 ± 0.64	7 (24)	19
	Pre-knowledge about ET	4 (11)	8	5.81 ± 1.80	1.88 ± 0.62	2.31 ± 0.71	2 (7)	3

^aValues are mean ± SD.

2012). The aim was to acquire an understanding of the most stressful event or experienced daily problems. All diaries were read several times by the first author (SAK) for an overall understanding of the content. The text was divided into meaning units; then, it was condensed into categories and subcategories of stressful events or experienced problems for that specific day. These categories and subcategories were then discussed among the co-authors (CW, IH) and revised as appropriate. All categories and subcategories were cross-checked against the meaning units and comparisons, and cross-checks of the data were made between the three reported months to determine similarities or differences (Krippendorff, 2012).

2.4.2 | Quantitative analysis

Descriptive statistics were used to present participants' demographic characteristics. The frequency of each category for each patient was calculated and reported as the mean number of registrations per month and the standard deviation (SD). For each category, the distress level, control level, level of expectation and coping strategies were calculated and reported as mean values with SD using Excel; Microsoft, Redmond, WA, USA. Coping strategies were calculated and reported as the number and per cent of patients using each coping strategy (Krippendorff, 2012).

2.4.3 | Ethical considerations

Patients were informed, in accordance with the Declaration of Helsinki (World Medical A, 2002), that participation was voluntary and could be terminated at any time without consequences. They

were also assured that their confidentiality would be respected throughout the research process. When presenting the results, efforts were made to maintain confidentiality by carefully weighing the use of informative yet non-identifiable quotations in the text. This study was approved by the Regional Ethics Committee in Gothenburg (approval no 792-16).

3 | RESULTS

The median age of the participants was 63 years. Most of the patients were prescribed TAM (72%) as ET (Table 1).

3.1 | Qualitative results

3.1.1 | Stressful events or experienced problems a specific day

Physical problems

The most reported problem was *physical problems*. Patients reported a variety of *physical problems* such as *sleeping difficulties*, *pain*, *cramps*, *stiffness* and *hot flashes*. *Sleeping difficulties* was reported as the most stressful event among the physical symptoms. It included waking up in the middle of the night due to hot flashes or not being able to sleep. The patients described themselves to be tired in a strange way. This was considered as stressful for patients who experienced these difficulties, as the lack of sleep affected their next day due to a lack of energy. *Pain*, *cramps* and *stiffness* were also reported in the diaries as a frequent problem, described as cramps in the middle of the night. Also, headaches and dizziness were reported as a stressful event or problem. The category of

Distress ^a	Level of expectation ^a	Level of control ^a	Third month				
			n = 24;n (%)	Frequency	Distress ^a	Level of expectation ^a	Level of control ^a
4.38 ± 2.28	2.62 ± 1.34	2.56 ± 1.28	21 (86)	286	3.81 ± 2.08	2.84 ± 1.49	2.53 ± 1.29
4.20 ± 2.19	2.60 ± 1.32	2.44 ± 1.23	15 (63)	89	4.24 ± 2.21	2.68 ± 1.33	2.54 ± 1.24
4.32 ± 2.21	2.43 ± 1.22	2.63 ± 1.30	15 (63)	93	3.48 ± 1.84	2.56 ± 1.34	2.54 ± 1.26
3.42 ± 1.43	2.46 ± 1.02	2.52 ± 1.03	7 (29)	28	4.36 ± 1.75	2.38 ± 0.95	2.68 ± 1.04
4.5 ± 1.0	2 ± 0.50	3 ± 0.66	2 (8)	8	3.75 ± 0.84	2.33 ± 0.54	2.67 ± 0.59
4.67 ± 1.04	1.67 ± 0.40	2.83 ± 0.63	2 (8)	11	3 ± 0	2 ± 0	3 ± 0
4.67 ± 2.23	3 ± 1.42	2.60 ± 1.22	9 (33)	57	4.14 ± 1.94	3.02 ± 1.28	2.44 ± 1.05
4.99 ± 2.59	2.49 ± 1.27	2.42 ± 1.25	13 (54)	58	4.34 ± 2.16	2.73 ± 1.36	2.55 ± 1.22
4.94 ± 2.49	2.45 ± 1.24	2.47 ± 1.24	12 (50)	44	4.46 ± 2.17	2.67 ± 1.31	2.49 ± 1.17
4.40 ± 1.76	2.37 ± 0.97	2.24 ± 0.90	3 (13)	6	3.44 ± 0.92	2.33 ± 0.64	2.33 ± 0.64
6.5 ± 1.44	4 ± 0	3 ± 0.66	3 (13)	8	4.9 ± 1.42	3.33 ± 0.90	3 ± 0.80

digestive organ symptoms included reports of nausea after receiving ET. Moreover, patients described bothering flatulence as a stressful event or problem. Lower abdomen and genital symptoms were reported by the women including dryness, burns, itches, soreness and urinary retention. Infection was reported as surgical site infections. Hot flashes were reported as a form of life disturbance that also affected patients' social lives when the flashes led to sweating and wet clothes, as well as negatively affecting their sleep at night (Table 2).

Emotional problems

Anxiety, irritation and pre-knowledge were categorized as emotional problems. Anxiety included fear of cancer relapses and feelings of sadness because of the breast cancer diagnosis. Patients specifically reported cancer anxiety and fear when unable to continue their treatment because of side effects. Depressive feelings were also reported by several participants. Irritation was reported as a problem and included being angry or annoyed at everyone. Mood swings and feelings of frustration were also reported. Pre-knowledge about ET was described as hesitation towards continuing ET and not wanting to be a "part-time bitch" (Table 2).

3.2 | Quantitative results

3.2.1 | Stressful events or experienced problems, number of reports and frequencies

The most common event or problem, reported by the largest number of patients, was sleeping difficulties in the category physical symptoms. Thirty-four per cent of patients reported emotional problems (Table 3).

3.2.2 | Distress level, control level and level of expectation

The overall reported distress level was somewhat higher in the second month (mean 4.1) compared with the first month (mean 3.9) and the third month (mean 3.7).

Although hot flashes were expected, they were associated with the lowest level of control. The least expected stressful event or experienced problem was infection (Table 3).

3.2.3 | Use of coping strategies

The patients reported using coping strategies to cope with the reported stressful events or problems that were pre-defined in the DCA. Over the three months, the most frequently used coping strategy was accepting the problem (Table 4), except to cope with problems concerning lower abdomen and genital organs symptoms, anxiety and irritation. The most commonly used strategies for these problems were to think of something else.

4 | DISCUSSION

The present study demonstrated a variety of stressful events related to ET over time and a wide variety in coping strategies. The most reported stressful event or reported problem was sleeping difficulties, which was handled by relaxation and acceptance. Sleeping difficulties have been identified as affecting patients' ability to continue treatment with AI, if reported the first month of treatment (Nabieva, Fehm, & Haberle, 2018). Further, side effects during the first month can affect patients' ability to stay

TABLE 4 Number of Coping Strategies related to ET, normalized to number of reported symptoms over the three months

Stressful events or problems (number reported over three months)	Thought about something else	Looked at the problem in a different way	Did something about it	Expressed emotions (Catharsis)	Accepted the problem	Sought support from others	Relaxed	Sought spiritual support	Other ways of coping
Physical Problems	43,1%	22,8%	39,6%	11,0%	63,3%	16,0%	35,5%	9,6%	11,6%
Sleeping difficulties (n = 272)	51,1%	24,6%	33,5%	17,3%	58,5%	19,9%	52,2%	9,9%	5,9%
Pain, cramps, stiffness (n = 254)	32,7%	16,5%	47,6%	9,8%	58,3%	13,0%	35,0%	9,4%	9,8%
Digestive organs symptoms (n = 86)	41,9%	20,9%	46,5%	5,8%	50,0%	4,7%	22,1%	22,1%	24,4%
Lower abdomen and genital organs symptoms (n = 15)	60,0%	26,7%	66,7%	0%	40,0%	26,7%	6,7%	0%	66,7%
Infection (n = 32)	3,1%	0%	15,6%	0%	18,8%	6,3%	12,5%	0%	3,1%
Hot flashes (n = 250)	49,6%	30,4%	37,2%	9,2%	85,2%	19,2%	27,2%	6,8%	12,8%
Emotional Problems	56,9%	37,9%	31,8%	28,7%	50,8%	31,3%	28,2%	7,2%	4,6%
Anxiety (n = 145)	57,9%	39,3%	33,8%	25,5%	51,7%	31,7%	26,2%	5,5%	3,4%
Irritation (n = 31)	67,7%	32,3%	16,1%	35,5%	58,1%	12,9%	45,2%	12,9%	0%
Pre-knowledge about ET (n = 19)	31,6%	36,8%	42,1%	42,1%	31,6%	57,9%	15,8%	10,5%	21,1%

in treatment for its full duration (Wallwiener, Nabieva, & Feisst, 2019). Lower treatment control beliefs significantly decrease the ability to stay in treatment (Corter, Broom, Porter, Harvey, & Findlay, 2018). Moreover, depressive symptoms and lack of social relations increases the risk of not being able to accept ET and patients may cope through avoidance, which might not be helpful (Bright & Stanton, 2018). However, the results from this study highlight patients' capability to *think about something else* or *look at the problem in a different way*, as coping strategies that can help manage *anxiety*. This indicates that patients used both problem- and emotion-focused coping strategies (Lazarus & Stress, 1984). These findings are similar to the results of earlier studies that used different target groups, that is chemotherapy as adjuvant therapy after breast cancer surgery or abdominal cancer surgery (Browall, Persson, Ahlberg, Karlsson, & Danielson, 2009; Smith, Ohlen, Persson, & Carlsson, 2018).

Previous research suggests that early termination of ET is related to side effects, indicating that starting the treatment can be very stressful (Corter et al., 2018; Nabieva et al., 2018). To capture both the start of treatment and the following time, we measured for 90 consecutive days and found that the distress level was higher the second month of ET. This indicates the importance acknowledging the women's experience of ET over time and not only at start of treatment.

Our results highlight the diversity of experiences of side effects as many patients reported different side effects from one day to the next, with substantial variance in how distressful the event was perceived. Previous studies have reported hot flashes, night sweats, fatigue, mood swings and weight loss/gain (Moon et al., 2017), as well as musculoskeletal symptoms and sleeping disorders (Laroche et al., 2017). However, a strength of this study was that data were collected for a longer period of time than in previous studies. In sum, to identify individualized patient experiences with ET, a collaborative relationship between patients and healthcare professionals is vital (Farias, Ornelas, & Hohl, 2017).

4.1 | Study limitations

Selection bias is possible because only 47 of 53 patients agreed to participate and the final cohort included only 39 patients and only 35 patients returned their first diary with written text. There could also be a bias as seven patients withdraw their participation during the measurement period. For three patients, this was related to a lack of stressful events or problems to report. Of the seven patients who withdraw their participation, the median age was 66 years (range 48 – 81).

Even though the diary did not specify the relation between their treatment and experienced stressful events or problems, the patients were given oral instructions by the first author (xx), when included in the study. However, this could imply that some of the reported stressful events or problems like *hot flashes* and *sleeping difficulties* could be either related to treatment or related to typical ageing. Furthermore, we did not ask the patients if they considered their coping strategies

to be effective in managing stressful events or problems. In future research, this question can add important information.

4.2 | Clinical implications

The knowledge from this study can be used when informing patients of possible side effects or problems associated with prescribed ET. The described stressful events and experienced problems ranged from no problems to varying problems related to ET. This is important knowledge when informing patients about their treatment, as the information has to be adapted to the individual patient's experience of ET.

5 | CONCLUSION

A key contribution is the real-time reports about the severity of experienced stressful events. Our results highlight the importance of exploring individuals' experiences of stressful events or experienced problems during ET. It is vital for healthcare professionals to identify patients' capacities and acknowledge their capabilities. The results stress that support needs to be based on individualized experiences of ET and patients' personal needs, which can vary over time.

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CONFLICTS OF INTEREST

The authors have no conflicts of interest to disclose.

AUTHOR CONTRIBUTIONS

IH, SAK, ROB, CW: Conceptualization and design. IH, SAK, CW: Methodology. SAK: Data collection. IH, SAK, CW: Formal analysis. IH, SAK, CW: Visualization. IH, SAK, ROB, CW: Writing–review and editing.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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