



360 Health Analysis - Breast Cancer Management in Portugal: Patient Journey

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An overview of H360 Phase 2 study that analysed hospital organisation and performance on breast cancer management from the perspective of patients, health care professionals and hospital decision-makers.

Introduction

360 Health Analysis (H360) was started in 2018 with the aim of providing a comprehensive picture of breast cancer management in Portugal by retrieving real-world data from Portuguese hospitals. Phase 1 of this project consisted in a comprehensive review of the state of the art regarding clinical practice, management, and quality of care in breast cancer in Portugal (Coelho et al. 2020).

H360 Phase 2 intends to document how the Portuguese health system currently performs regarding breast cancer management, from screening and diagnosis to treatment and follow-up. It also aims to identify the main difficulties experienced by the health system in this endeavour and put forward an integrated multi-institutional action plan on how to improve

breast cancer management in Portugal. To do so, the present study analysed hospital organisation and performance regarding breast cancer management from the perspective of patients, health care professionals (HCPs; clinicians and non-clinicians), and hospital decision-makers. The study aim was to analyse how patients perceive their journey within the health system, from breast cancer diagnosis to treatment and follow-up, and also how HCPs and hospital decision-makers perceive the journey of these patients within their institutions. Data regarding both these aspects represents an unmet need in Portugal, as there is a clear lack of literature and studies on the subject. European and international studies published in this area are scarce and usually related to the process of breast cancer diagnosis (Heisey et al. 2011; Burgess et al. 1998; Arndt et al. 2003).

Methodology

This study was approved by the Administration Boards of participating hospitals following approval by the respective Ethics Committees and its design and conception were of the strict responsibility of study investigators. Voluntary surveys were carried out to breast cancer patients and face-to-face interviews to HCPs and hospital decision-makers in Portuguese hospitals. Of 10 initially selected hospitals, three were excluded due to successive bureaucratic and Ethic and Data Protection Commission response delays and seven were included, comprising general university hospitals (n=1), district hospitals (n=3), oncology institutes (n=2), and private hospitals (n=1). Hospital institutions were anonymised to ensure data privacy.

1. Patient surveys

Patient inclusion criteria for participating in the survey included women (i) with breast cancer diagnosis, (ii) aged ≥ 18 years old, (iii) with a first cancer diagnosis, (iv) with breast cancer diagnosis ≥ 6 months and ≤ 5 years ago, and (v) able to provide written informed consent. No exclusion criteria were set. Sampling was done by convenience for patients attending the Oncology consultation, meeting study inclusion criteria, and accepting to participate in the study. The intention was to select a 3:4 proportion of patients with early and advanced stage disease.

Based on the initial hospital sample of 10 hospitals and in the 1.72% prevalence of breast cancer in Western Europe (Bray et al. 2013), the estimated sample size was between 263 and 332 patients. Sample estimation was set for a bilateral test, with 0.05 probability of type I error and 0.95 potency. G*Power® Software was used for calculations. Based on these considerations, sample size was 300 patients. After exclusion of three hospitals and considering the number of patients answering the survey (n=98), study potency was set at 0.84.

Patients received the survey either by email or telephone between 1 and 23 of June 2020. Online interviews were carried out with Computer Assisted Web Interview (CAWI) system and phone interviews with Computer Assisted Telephone Interview (CATI) system. Quantitative study using descriptive and comparative statistics was subsequently performed using SPSS® software.

2. Health care professional (HCP) interviews

To gain insights from HCPs on patients' journey within the health system, including main barriers and facilitators, a qualitative methodology was used, through implementation of semi-structured interviews with presentation of a standardised case vignette.

Inclusion criteria comprised professionals (i) with direct intervention in breast cancer care in the study hospitals (ii) belonging to one of the following professional categories: diagnostic technician, nurse, nutritionist, operational assistant, pharmacist, psychologist, physician, physiotherapist, social worker, or technical assistant.

HCPs meeting inclusion criteria were randomly invited to participate in the study on the day of study interview until the pre-defined sample size for each hospital was reached. Considering the number of professional categories established in inclusion criteria, the prespecified sample size was three HCPs *per* hospital, in a total of 30 HCPs. Qualitative analysis of interview contents was subsequently performed based on breast cancer patient journey.

3. Hospital decision-maker interviews

To retrieve the perspective of hospital decision-makers regarding hospital procedures and performance in breast cancer management, a qualitative methodology was used, through implementation of semi-structured interviews.

Inclusion criteria comprised professionals (i) performing hospital decision-maker functions (ii) in one of the following settings: Administration Board, Management Support Unit, Department direction, or Clinical management/direction. Sample was prespecified at one hospital decision-makers *per* hospital, in a total of 10. Qualitative analysis of interviews' contents was subsequently carried out.

Results

1. Patient surveys

1.1 Hospital selection and patient interviews

A total of 155 patients accepted to participate and were enrolled in the study. Of these, 98 patients were successfully contacted, either by email or telephone. The flowchart of patient enrollment is depicted in Figure 1.

1.2 Patient socio-demographic characterisation

The median age of women included in this study was 59 (range 35–85) years old and most lived in the north of Portugal (33%) or Lisbon (32%; Table 1). Regarding household, 44% of women lived in households of two people, 23% of three, 13% of four or more, and 20% of patients lived alone. A significant proportion of women (58%) were married or lived with a partner, 16% were single, 13% were divorced, and 13% were widows. The predominant household net monthly income was ≤ 800 € (30%), followed by 800–1200€ (23%). Most women (81%) had descendants (two descendants in 41% of cases and one descendant in 40% of cases). Most women (53%) had their breast cancer diagnosed < 4 years ago and 42% ≥ 4 years ago. Regarding disease stage, 68% of women had localised breast cancer, 5% locally advanced disease, 22% metastatic disease, and 5% were not aware of their disease stage. Socio-demographic characterisation and disease stage of the study population is further detailed in Table 1.

1.3 Commuting and hospital waiting times

The main mode of transportation to and from the hospital for treatment purposes was patients' own vehicle (42%), with 21% of patients depending on ambulance transportation and 15% on

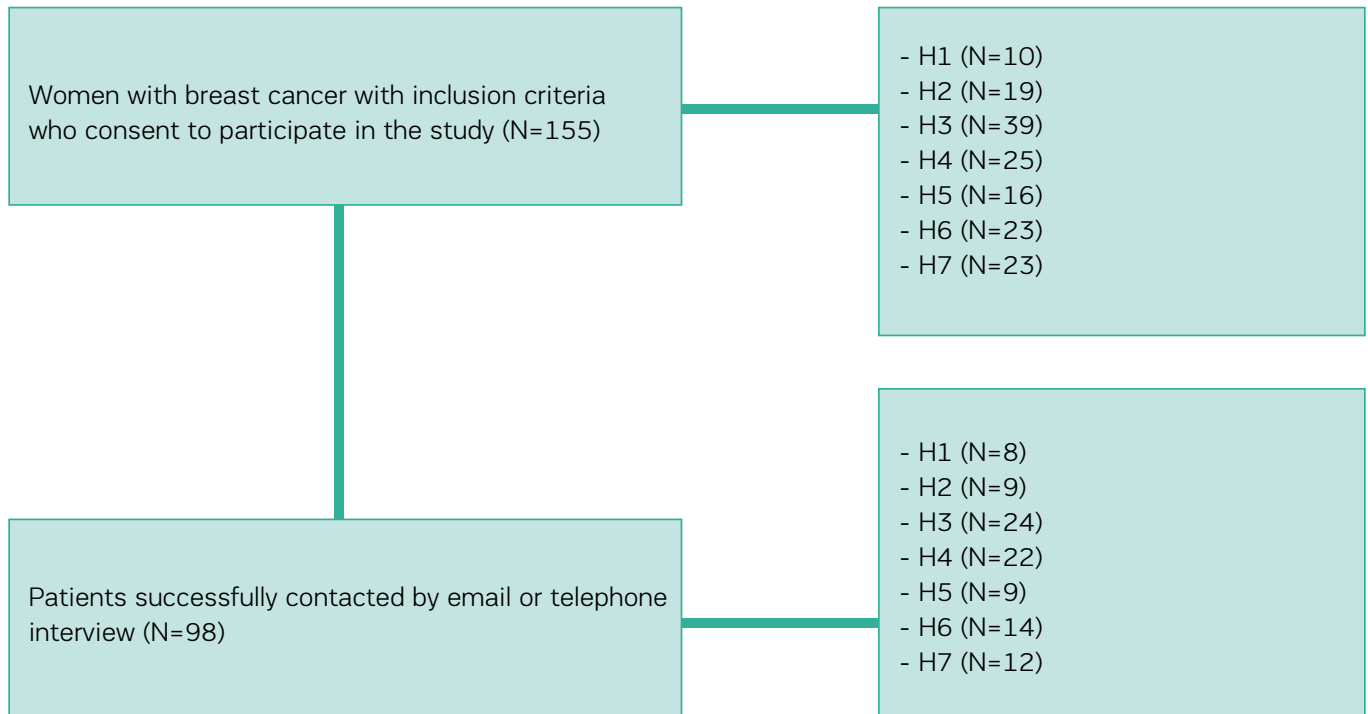


Figure 1. Flowchart of breast cancer patients included in the study.

public transports (Table 2). The total commuting time to and from the hospital was highly variable, with patients spending between 10 minutes to 2 hours in the process (Figure 2). Within the hospital, time spent waiting for treatment start was also variable, with 56% of patients reporting waiting less than 60 minutes and 26% less than 20 minutes (Figure 2). Time spent on treatment was the most variable parameter, in agreement with the high diversity of treatments used in breast cancer (Figure 2). Patient commuting times and hospital waiting times are presented in Table 3.

Most women (63%) were accompanied while going to treatment, 47% by their partners (Table 4). About 1 in every 3 women went to treatment alone.

The number of monthly treatments was highly variable, ranging between less than 1 to 60, presumably due to diversity of breast cancer treatments. Thirty percent of women took medication on a daily basis (Table 5). Women ≥ 60 years old were those receiving the greatest number of monthly treatments, possibly due to the great incidence of hormone therapy treatments in the elderly, which can be performed orally and at home.

1.4 Last day of hospital treatment and number of hospital desks visited

Patients were also asked about their experience in the last day of treatment in the hospital. The number and type of hospital

desks visited during the last day of treatment was variable, with most patients referring having visited 1 (44%) or 2 (36%) desks (Table 6).

The type of desks visited varied according to hospital (Figure 3). For most patients, the first desk visited was the front desk (88%) and the second was predominantly either the nurse station (33%) or the clinical analysis (28%) desk. For women who visited a third desk, this was the medical oncologist desk or the Day Hospital treatment facility desk (28% each). Thirty-three percent of women visited a fourth desk, mainly the front desk, the nurse station desk, or the medical oncologist desk (33% each). Desk waiting times were generally low (less than 10 minutes), except in the fourth desk, in which 10 to 40 minutes of waiting time were reported (Figure 4).

1.5 Impact of treatment on professional life

A total of 18% of women with breast cancer continued to work while receiving treatment for their disease, particularly those with less than 60 years of age (HR 7.25, 95% CI 1.4–38.3, $p=0.020$), with 40% of working women reporting having never missed work (Table 7). Most of these women had less than 60 years of age and considered that keeping an occupation was positive for their health. Of note, a significant proportion of women (44%, $n=43$) resorted to medical leave during breast cancer treatment, particularly women less than 60 years old (HR 0.21, 95% CI 0.09–0.52, $p=0.001$), and 7% ($n=3$) continued working despite being on medical leave.

Age – median (range)	59 years (35–85)	Age – median (range)	59 years (35–85)
Socio-demographic characterisation		Socio-demographic characterisation	
Geographic area of residency – N (%)		Net household monthly income – N (%)	
North	32 (33)	≤800€	19 (30)
Center	10 (10)	800–1200€	15 (23)
Lisbon	31 (32)	1201–1600€	9 (14)
Alentejo	12 (12)	1601–2000€	3 (5)
Algarve	13 (13)	2001–2400€	6 (9)
Hospital – N (%)		≥2401€	12 (19)
Hospital 1	8 (8)	NR	34
Hospital 2	9 (9)	Descendants – N (%)	
Hospital 3	22 (23)	Yes	79 (81)
Hospital 4	24 (25)	No	19 (19)
Hospital 5	9 (9)	Number of descendants – N (%)	
Hospital 6	14 (14)	1	32 (40)
Hospital 7	12 (12)	2	32 (40)
Household – N (%)		3	9 (12)
1	20 (20)	≥4	6 (8)
2	43 (44)	Disease Stage – N (%)	
3	22 (23)	Localised	67 (68)
≥4	13 (13)	Locally advanced	5 (5)
Marital Status – N (%)		Metastatic	21 (22)
Single	15 (16)	NR	5 (5)
Married or living with partner	57 (58)		
Divorced	13 (13)		
Widow	13 (13)		

Table 1. Study population socio-demographics, risk factors, and disease characteristics IUD, intrauterine device; NR, no response

2. HCP interviews

A total of 22 HCPs were interviewed (four from one hospital and three from the remaining six hospitals), mostly women (86.4%) and with a mean age of 40.7 years (range 27–60). Half (50%) of participants were married and 21 (95.5%) lived in urban areas. Regarding educational level, 4.5% (n=1) had 7–9 school years, 18.2% (n=4) had 10–12 school years, 31.8% (n=7) had a bachelor degree, 40.9% (n=9) had a master degree, and 4.5% (n=1) had a doctoral degree. Regarding professional categories, 7 (31.8%) HCPs were physicians, 5 (22.7%) were nurses, 3 (13.6%) were operational assistants, 3 (13.6%) were pharmacists, 2 (9.1%) were technical assistants, 1 (4.5%) was a social worker, and 1 (4.5%) was a psychologist. Twenty (90.9%) respondents worked as HCPs and the remaining (n=2; 9.1%) mainly performed management functions. Regarding the type of contract with the employer, 10 (47.6%) had an unfix-term employment contract, 7 (33.3%) had a permanent

contract, and 4 (19.0%) had a fixed-term employment contract. Concerning working schedule, 6 (84.2%) had fixed working hours and 3 (15.8%) had rotating working hours. Six (27.3%) respondents worked elsewhere.

2.1 Breast cancer patient journey in the health system

HCPs were asked their perception about breast cancer patients' journey within their institutions, from disease clinical suspicion to confirmatory diagnosis, treatment, and follow-up. For most hospitals, primary health care is the main source of patient referral to the hospital. Patients receive information about their diagnosis mostly from the surgeon and occasionally from the medical oncologist. Most hospitals have a multi-disciplinary team working in collaboration in treatment decisions. Some hospitals accept and refer patients for medical appointments after an initial multidisciplinary or Oncology meeting, while others undertake the medical appointment



Way of commuting to and from the hospital	Total N=98	H1 N=8	H2 N=9	H3 N=24	H4 N=22	H5 N=9	H6 N=14	H7 N=12
Own vehicle	42	25	11	33	50	22	57	75
Ambulance	21	13	33	38	5	56	14	---
Public transport	15	13	22	13	27	11	14	---
Vehicle from a family member or friend	9	38	---	4	18	---	---	8
On foot	5	---	11	4	---	11	14	---
Home treatment	4	13	11	4	---	---	---	8
Taxi	2	---	---	4	---	---	---	8
NR	1	---	11	---	---	---	---	---

Table 2. Commute to and from the hospital according to age group and hospital H, hospital; NR, no response

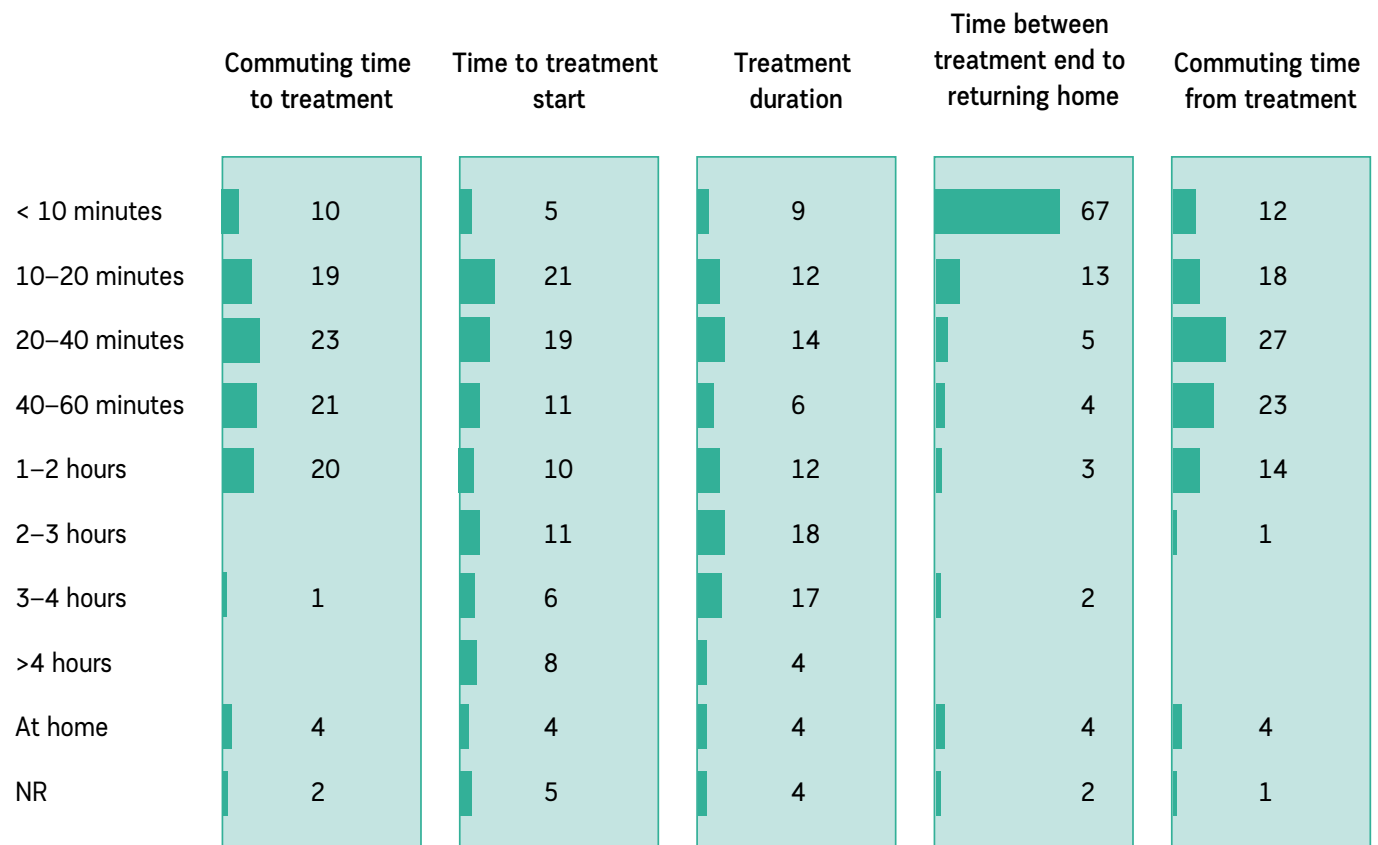


Figure 2. Commuting times and in-hospital waiting times (%)

In-hospital waiting times and commuting times	Total	H1	H2	H3	H4	H5	H6	H7
	N=98	N=8	N=9	N=24	N=22	N=9	N=14	N=12
Commuting time to treatment								
< 10 minutes	10	---	11	8	9	11	21	8
10-20 minutes	19	---	---	13	27	33	29	25
20-40 minutes	23	25	11	17	27	44	7	33
40-60 minutes	21	38	33	21	14	11	21	17
1-2 hours	20	25	22	38	18	---	14	8
2-3 hours	---	---	---	---	---	---	---	---
3-4 hours	1	---	---	---	5	---	---	---
>4 hours	---	---	---	---	---	---	---	---
NR	2	---	11	---	---	---	7	---
Time to treatment start								
< 10 minutes	5	---	---	4	9	---	---	17
10-20 minutes	21	13	---	33	18	22	---	42
20-40 minutes	19	25	67	8	18	---	21	8
40-60 minutes	11	25	11	8	14	---	14	8
1-2 hours	10	---	---	8	14	22	14	8
2-3 hours	11	---	---	4	14	33	21	8
3-4 hours	6	---	---	17	5	---	7	---
>4 hours	8	13	---	8	9	11	14	---
NR	5	13	11	4	---	11	7	---
Treatment duration								
< 10 minutes	9	13	22	8	9	22	---	---
10-20 minutes	12	---	11	25	9	---	14	8
20-40 minutes	14	38	11	---	18	---	14	33
40-60 minutes	6	---	---	4	9	---	14	8



1-2 hours	12	25	---	13	---	11	36	8
2-3 hours	18	---	11	13	18	44	7	33
3-4 hours	17	13	11	29	27	11	---	---
>4 hours	4	---	---	---	5	11	14	---
NR	4	---	22	4	5	---	---	---
Time between treatment end and returning home								
< 10 minutes	67	88	44	63	68	56	86	58
10-20 minutes	13	---	---	13	18	11	14	25
20-40 minutes	5	---	11	---	5	22	---	8
40-60 minutes	4	---	11	8	---	11	---	---
1-2 hours	3	---	---	8	5	---	---	---
2-3 hours	---	---	---	---	---	---	---	---
3-4 hours	2	---	---	4	5	---	---	---
>4 hours	---	---	---	---	---	---	---	---
NR	2	---	22	---	---	---	---	---
Commuting time from treatment								
< 10 minutes	9	13	22	8	9	22	---	---
10-20 minutes	12	---	11	25	9	---	14	8
20-40 minutes	14	38	11	---	18	---	14	33
40-60 minutes	6	---	---	4	9	---	14	8
1-2 hours	12	25	---	13	---	11	36	8
2-3 hours	18	---	11	13	18	44	7	33
3-4 hours	17	13	11	29	27	11	---	---
>4 hours	4	---	---	---	5	11	14	---
NR	4	---	22	4	5	---	---	---

Table 3. Patients' commuting and hospital waiting times, by hospital H, hospital; NR, no response

Accompaniment to treatment	Total N=98	H1 N=8	H2 N=9	H3 N=24	H4 N=22	H5 N=9	H6 N=14	H7 N=12
No accompaniment	37	25	22	50	32	78	21	25
Significant other	31	13	33	21	36	22	29	58
Son/daughter	18	13	22	21	18	---	29	17
Father/mother	9	---	11	4	9	11	29	---
Sibling/ sibling-in-law	9	25	---	4	14	---	14	8
Friend	7	13	---	4	18	---	7	---
Home treatment	4	13	11	4	---	---	---	8
Other family members	1	---	---	4	---	---	---	---
NR	1	---	11	---	---	---	---	---

Table 4. Accompaniment to breast cancer treatment according to age group and hospital H, hospital; NR, no response

Number of monthly treatments	Total N=98	H1 N=8	H2 N=9	H3 N=24	H4 N=22	H5 N=9	H6 N=14	H7 N=12
<1	5	---	11	4	5	---	---	17
1	19	50	11	17	9	44	29	---
2	19	13	11	21	23	---	36	17
3	2	---	11	---	5	---	---	---
4	11	---	---	4	27	11	7	17
5-22	12	---	---	25	5	11	7	25
Daily	27	25	44	29	18	33	21	25
Twice a day	2	13	---	---	5	---	---	---
NR	2	---	11	---	5	---	---	---

Table 5. Number of monthly treatments according to age group and hospital H, hospital; NR, no response



Number of desks	Total	H1	H2	H3	H4	H5	H6	H7
	N=98	N=8	N=9	N=24	N=22	N=9	N=14	N=12
1 desk	44	38	33	54	36	44	50	42
2 desks	36	50	33	29	45	44	21	33
3 desks	15	13	22	13	9	11	29	17
4 desks	2	---	---	---	5	---	---	8
5 desks	1	---	---	---	5	---	---	---
NR	2	---	11	4	---	---	---	---

Table 6. Number of desks visited in the last hospital treatment H, hospital; NR, no response

with the surgeon or medical oncologist first and the multidisciplinary group meeting afterwards. One hospital has a dedicated Breast Cancer Clinic, where surgeons, medical oncologists, radiotherapists, and nurses work in coordination. In another hospital, patients are referred, not only to designated breast cancer treatment specialties, but also to Phycology and Nutrition support after diagnosis. Breast cancer patient journey according to hospitals from HCP perspective is detailed in Table 8.

2.2 Main barriers and facilitators in breast cancer patient journey

The main barriers identified by HCPs from National Health Service (NHS) hospitals regarding breast cancer patient journey were an excessive number of patients to the availability of technical and human resources and lack of adequate work facilities. Long waiting times for Imaging scheduling and respective results, analytic and pathology results, and surgery scheduling were also commonly acknowledged barriers. Insufficient treatment seats in Day Hospital for chemotherapy and other oncology treatments was a common concern. Shortage of human and technical resources and proper working facilities were pointed out as main reasons for HCP’s overwork and exhaustion and for lack of adequate response regarding imaging, pathology, other complementary diagnostic exams, surgery times, and cancer treatments.

The main facilitators in breast cancer patient journey varied according to hospital. One hospital acknowledged the presence of a multidisciplinary structure focused on breast cancer treatment, as well as the availability of all necessary patient resources in all stages of the disease. Another hospital denoted the good Day Hospital functioning and the

availability of a software for optimising waiting times since the first breast cancer appointment to treatment start. HCPs at one hospital acknowledged a functional system for treatment and appointment scheduling and a convenient and patient-friendly outpatient pharmaceutical system. HCPs at another hospital acknowledged the availability of plenty of room in their facilities and the benefit of double-checking analytic results. One hospital acknowledged the importance of multidisciplinary team discussions and efficient inter-specialty communication and the good relationship between professional team and patients. Another hospital referred its highly motivated professionals and good working relationship, existence of a functional Day Hospital and Nursing consultation, and the possibility of performing non-scheduled consultations. Finally, private sector hospital recognised the advantage of a functional insurance system and, contrarily to most NHS hospitals, prompt breast cancer diagnosis, staging, and treatment, with short waiting times.

The main barriers and facilitators in breast cancer patient journey according to HCPs by hospital are detailed in Table 9.

3. Hospital decision-maker interviews

From a total of 10 initial hospital decision-makers, three were excluded for successive delays in in-hospital study approvals and two for not answering the questionnaire. A total of five hospital decision-makers accepted to participate and completed the study questionnaire.

3.1 Positive aspects

The main positive aspect pointed out was the availability of a widely available multidisciplinary disease management structure supported by an experienced breast cancer team.

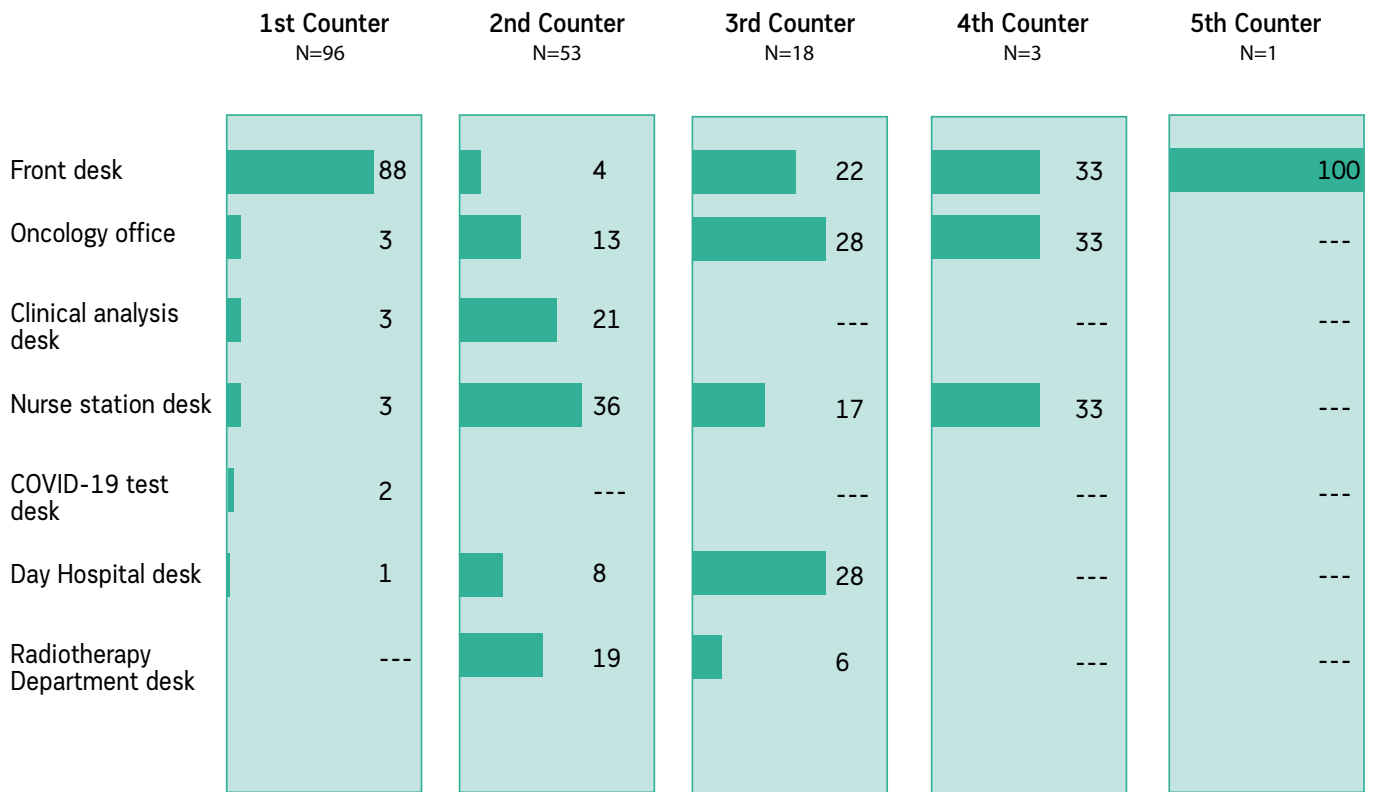


Figure 3. Number and type of hospital desks visited by patients during the last hospital treatment (%)

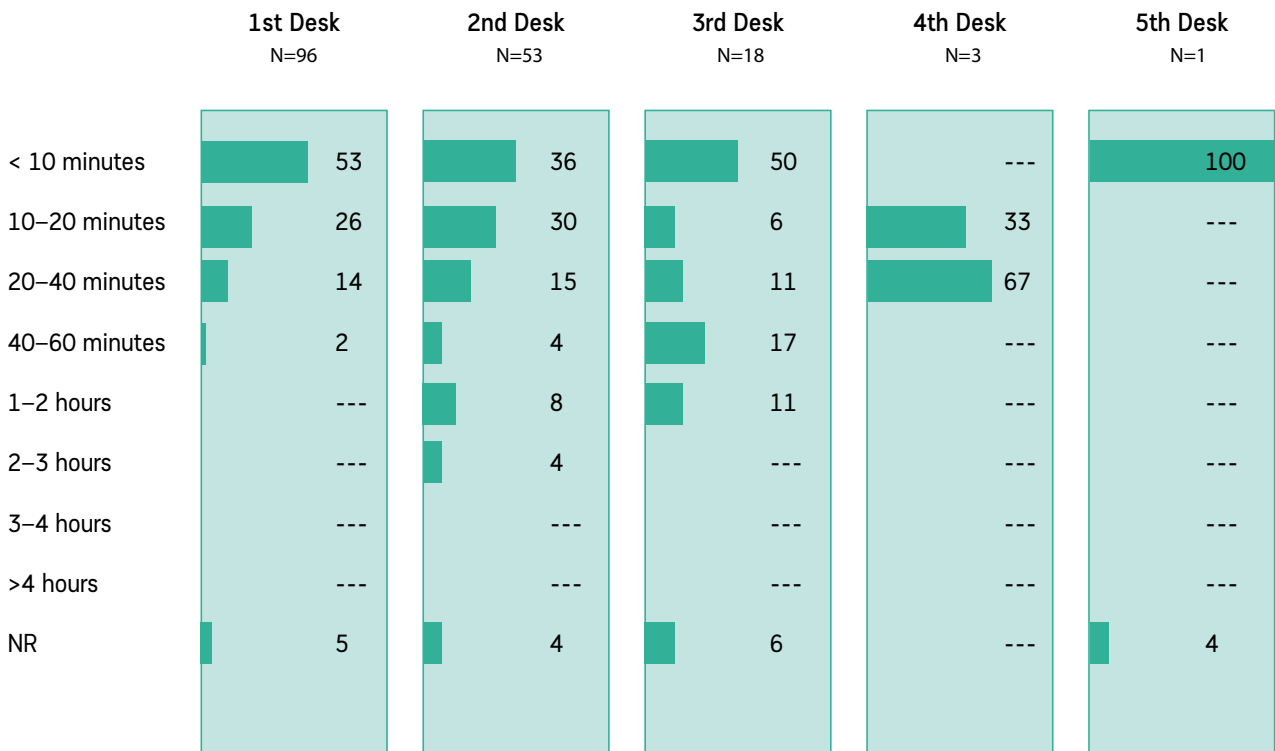


Figure 4 – Patient-reported waiting times in hospital desks during the last hospital treatment (%)



	Total	Patients <60 years old	Patients ≥60 years old	p-value
	N=98 (%)	N=57 (%)	N=40 (%)	
Medical leave				
Yes	43 (44)	33 (58)	9 (23)	0.001
No	55 (56)	24 (42)	31 (78)	
Kept working during treatment				
Yes	10 (18)	8 (33)	2 (7)	0.02
No	45 (82)	16 (67)	29 (93)	
Work absenteeism				
Never missed work	4 (40)	2 (25)	2 (100)	0.20
Missed work a few times	3 (30)	3 (38)	---	
Missed work several times	3 (30)	3 (38)	---	
Working while on medical leave				
Yes	3 (7)	2 (6)	1 (11)	0.56
No	40 (93)	31 (94)	8 (89)	
Reasons for working during treatment				
Financial reasons	3 (23)	2 (20)	1 (33)	
Personal choice for health reasons	5 (46)	4 (40)	1 (33)	0.54
Absence of work backup/substitute	4 (31)	4 (40)	---	
No access to medical leave	1 (8)	---	1 (33)	

Table 7. Impact of treatment on professional life according to age group

All hospital decision-makers extensively considered that their hospitals had easy and rapid access to the Oncology center once diagnosis was established, with some also reporting a close doctor-patient relationship and ease in patients contacting the attending physician. One hospital emphasised the benefit of having established treatment protocols. One hospital stressed the ease and quickness in making appointments for Day Hospital treatments, absence of waiting list for Oncology consultations, and good hospital

infrastructures, and another hospital emphasised the highly motivated and work-committed doctors and HCPs at the Oncology Department.

3.2 Aspects to improve

The main aspects referred as requiring improvement were time until breast cancer diagnosis and staging due to difficulty in quickly obtaining complementary diagnostic test results. Time until treatment start, particularly surgery, was pointed out as

Hospital	Origin of hospital referral	Diagnosis	Hospital HCP receiving the referral	HCPs giving information to the patient and type of information given	In-hospital patient referral	Follow-up and surveillance
H1	- Primary health care	- Oncology surgeon	- Early-stage clinic physician and nurse	- Physician: clinical information - Nurse: doubt clarification, explanations and preparation for diagnostic and staging exams, and explanation of hospital functioning -Multidisciplinary team	- Breast Neoplasm Clinic - Day hospital - Radiotherapy Department	- Regular medical appointments according to undergoing treatment and patient's condition. - Follow-up based on alternate Oncology, Surgery, and Radiology consultations
H2	- Primary health care -Multidisciplinary meeting	- Assistant physician - Surgeon	- Physician - Surgeon	- Surgeon: diagnosis information - Physician: therapeutic decision	- Multidisciplinary team - Oncology consultation - Surgery consultation - Day hospital	- Biopsy - Regular medical appointments and diagnostic tests in different medical specialties
H3	- Primary health care - Oncology decision meeting	- Medical oncologist - Surgeon	- Medical oncologist - Surgeon	- Medical oncologist: clinical information and treatment plan - Surgeon	- Day hospital or hospital pharmacy (depending on the treatment plan) - Nursing consultation	- Guided by the Day Hospital with all treatment sessions scheduled, including radiotherapy
H4	- Primary health care - Surgeon - Private medicine - Multidisciplinary meeting	- Medical oncologist - Surgeon	- Medical oncologist - Surgeon	- Physician and Nurse	- Oncology consultation - Surgery consultation - Radiotherapy	- Staging - Clinical analytics and biomarkers
H5	- Primary health care	- Pathology - Surgeon	- Surgeon	- Family doctor: clinical information about the need for medical exams - Surgeon: diagnostic information and probable treatment options	- Oncology consultation	- Regular medical appointments with evaluation of patient's symptoms, physical examination and diagnostic and follow-up tests



H6	<ul style="list-style-type: none"> - Community screening - Senology - Primary health care 	<ul style="list-style-type: none"> - Senology Department (pre-biopsy) - Specialist doctor 	<ul style="list-style-type: none"> - Physician and Nurse (Senology Department) - Medical oncologist (Day Hospital) 	<ul style="list-style-type: none"> - Physician: diagnosis, treatment plan, and guidance within the Oncology department - Psychologist and nurse: collaborate in diagnostic information 	<ul style="list-style-type: none"> - Medical oncologist: diagnosis, treatment - Surgery: external hospitals - Radiotherapy - Day hospital - Psychology - Nutrition support 	<ul style="list-style-type: none"> - Surveillance every 3 months or every 6 months (if hormone therapy) - Surveillance of toxicities and treatment response. - Multidisciplinary team communication, if therapeutic adjustments are needed
H7	<ul style="list-style-type: none"> - Health care professionals - Surgeons - Multidisciplinary meeting 	<ul style="list-style-type: none"> - Family doctor - Radiologist Surgeon 	<ul style="list-style-type: none"> - Multidisciplinary meeting - Medical oncologist - Surgeon 	<ul style="list-style-type: none"> - Physician 	<ul style="list-style-type: none"> - Medical oncologist - Surgeon - National Health Care System Hospital 	

Table 8. Breast cancer patient journey according to HCPs H, hospital; HCP, health care professional

an aspect to improve, as well as time until radiotherapy start. One hospital acknowledged survivor follow-up and referral as aspects requiring improvement, while another hospital stressed the need to incorporate patient-reported outcomes in clinical assessment.

3.3 Aspects to modify

The main aspects requiring adjustments and improvement varied according to hospital. In one hospital, decision-makers considered that there should have a better and easier access to medical specialties not available at the center and stressed the need to implement oncofertility evaluation. In another hospital, waiting times for magnetic resonance imaging (MRI), namely breast MRI, were a relevant concern requiring improvement. One hospital pointed out the need for timely complementary diagnostic method results, better and larger infrastructures, and more HCPs, and private sector hospital referred insufficient insurance coverage as main aspect requiring improvement.

3.4 Resource availability

Resource shortage was mentioned by all public hospitals, in contrast with the private sector where lack of resources was not referred.

Hospital decision-makers generally referred a lack of human, technical, economic, and financial resources. Specifically, the need for more nurses, non-HCPs (particularly statisticians), and investigator study coordinators was mentioned by representatives of one hospital, who nevertheless referred having sufficient technical equipment at the institution. In this hospital, lack of economic and financial resources, as well as need for better working facilities and for improved and restructured budgetary allocation to improve drug policy were also stressed.

Additionally, shortage of human and financial resources, need for better working facilities and equipment, and need for more human and technical resources were also emphasized by participating hospitals.

Discussion

H360 Health Analysis is a pioneer project at national level that intends to comprehensively address aspects involved in breast cancer management in Portugal. As far as the authors are aware, no such study has been conducted in Portugal to date, particularly focusing hospital logistics and accessibility by breast cancer patients, and studies conducted in Europe and high-income countries are infrequent and mostly centered in primary care setting (Heisey et al. 2011; Burgess et al. 1998; Arndt et al., 2003).

In low- and middle-income countries, several initiatives are in place to improve accessibility of breast cancer patients to primary health care and hospitals, with the aim of reducing disparities between these countries and high-income counterparts, and ultimately impact breast cancer incidence and improve survival (Anderson et al. 2008). The Breast Health Global Initiative is a program directed at low- and middle-income countries involving the synergic work of breast cancer experts together with that of epidemiologists, health care administrators and politics, and clinical and translation researchers. (Anderson et al. 2008; Hortobagyi 2010). Understanding implementation and following the example of this type of program can be an example of how to improve health care delivery to breast cancer patients, particularly those with difficulties in hospital/health care system access (Anderson 2010). To do so, H360

Hospital	Barriers	Facilitators
H1	<ul style="list-style-type: none"> - Surgery and complementary exam results' waiting times - Disproportionate volume of patients to the availability of technical and human resources 	<ul style="list-style-type: none"> - Multidisciplinary structure based on the pathology on an organisational basis - All resources required to guide the patient at all stages of disease available
H2	<ul style="list-style-type: none"> - Difficulties in all stages of disease, from diagnosis to treatment, due to excessive bureaucracy, lack of human resources, and insufficient working facilities - Difficulty in transporting patients to the cancer center 	<ul style="list-style-type: none"> - Software in the final stage of development for optimisation of waiting times from the first appointment at the Oncology center to treatment start - Day Hospital treatments
H3	<ul style="list-style-type: none"> - Lack of human resources, namely pharmacists and other health care professionals, with consequent work overload for other professionals - Delays in treatment authorisation by the national regulatory authority - Disproportionate volume of patients to the availability of technical and human resources, with disproportionate geographic coverage - Long waiting times and insufficient treatment seats on Day Hospital - Delay in analytic results 	<ul style="list-style-type: none"> - Functional system for treatment and appointment scheduling - Practical outpatient pharmaceutical service - Collection of clinical analyzes the day before treatment
H4	<ul style="list-style-type: none"> - Long waiting times - Staff preparation 	<ul style="list-style-type: none"> - Plenty of space - Double-checked analytics
H5	<ul style="list-style-type: none"> - Different computer software with insufficient integration between primary care and hospital - Time spent by the doctor validating clinical processes and analytic results - Long drug preparation time in hospital pharmacy - Insufficient seats for all scheduled patients 	<ul style="list-style-type: none"> - Existence of a multidisciplinary team. Efficient inter-specialty communication - Good relationship between medical team and patients - Short waiting times
H6	<ul style="list-style-type: none"> - Radiology department with difficulty in responding to requests, with consequent postponement of consultations - Long waiting times to retrieve results of clinical analysis and Pathological Anatomy and to carry out treatments - Lack of human resources, namely health care professionals - Insufficient working facilities and non-functional physical distribution of departments within the hospital - Manual prescription of cancer treatments 	<ul style="list-style-type: none"> - Good working relationship between professionals and highly motivated professionals - Access to training (although mostly individually paid) - Functional nursing consultation to support patients and clarify their doubts - Availability of non-scheduled consultation - Easy access to Day Hospital treatment - Ongoing project to provide consultations and treatments by pathology
H7	<ul style="list-style-type: none"> - Difficulties in contacting the doctor 	<ul style="list-style-type: none"> - Functional insurance system - Promptness in diagnosis, staging, and required treatments

Table 9. Main barriers and facilitators in breast cancer patient journey according to HCPs H, hospital



was designed as a multiphase study involving patients and stakeholders (health care professionals and hospital decision-makers) participating in breast cancer management.

By providing a patient- and multi-stakeholder approach, this study retrieved relevant data for the future optimisation of breast cancer care in Portugal.

Patient accessibility to the hospital appears to be a relevant issue that should be improved. For instance, more than half of women used their own vehicle or public transport as main mode of commuting to and from the hospital, with 21% of patients depending on ambulance transportation. Commuting times to and from the hospital and waiting times until treatment start, although widely variable, were frequently longer than one hour. The need to reduce commuting and waiting times to treatment start is manifestly important, as the number of monthly treatments ranged between less than 1 to 60 for some women (even considering that some were performed orally and at home).

Training and humanisation of the staff involved in the care of these patients is of uttermost importance and should be a priority, as approximately one in every three women reported going to treatment alone. This is even more important regarding staff working in hospital front desks, as they frequently represent patients' first contact within health structures.

Concerning professional activity, studies about employment trends in women with breast cancer suggest that between 40% to 76% of women of working age have a job at the time of breast cancer diagnosis (Amir and Brocky 2009; Blinder et al. 2017; Jagsi et al. 2014; Jagsi et al. 2017), who will predictably experience difficulties in maintaining their jobs due to the disease (Blinder et al. 2017; Jagsi et al. 2017). According to a meta-analysis, 5.6% to 56.3% of women become unemployed after breast cancer surgery (Wang et al. 2018). Additionally, a significant proportion of women do not return to work after cancer (Jagsi et al. 2017; Bouknight et al. 2006). Substantial employment disruptions are particularly notorious for patients undergoing more aggressive treatments (Jagsi et al. 2017). Studies suggest that workplace accommodations and a non-discriminating work environment play a central role in returning to work (Bouknight et al. 2006). In the present study, 18% of women continued to work while undergoing breast cancer treatment and the Portuguese legislation falls short from protecting these women in terms of working rights, flexibility in working hours, and adjustment of working functions.

Regarding the approach to breast cancer management of hospitals analysed in this study, HCPs acknowledge the benefit of multidisciplinary disease management, which was a reality in all institutions. However, HCPs and hospital decision-makers from the NHS clearly acknowledged issues to be addressed. One of the main is the disproportionate number of patients for their institutions' capacity, either regarding facilities as technical or human resources. The long waiting times for performing complementary diagnostic exams and

obtaining results and for performing treatments referred by public hospitals are a major concern and significantly contrast to what is reported in the private sector. Difficulties in complementary diagnostic exams are an issue widely recognised both by HCPs and hospital decision-makers and should be tackled as a priority in the optimisation of breast cancer patients' care. On the other hand, medical health professionals reported difficulties in accessing innovative cancer therapies through the NHS. This is an important issue specifically addressed in the recently presented Europe's Beating Cancer Plan, which will hopefully help improve access to innovative cancer diagnosis and treatments across Member States (https://ec.europa.eu/commission/presscorner/detail/en/ip_21_342).

This study has limitations that should be acknowledged. Of ten hospitals initially selected, three were excluded due to bureaucratic and Ethic and Data Protection Commission response delays, with subsequent decrease in sample size. Also, due the study's mainly descriptive and qualitative nature, some qualitative information, particularly provided by HCPs and hospital decision-makers, may have been lost.

Conclusion

Issues uncovered by this study regarding patient accessibility and journey within health institutions are relevant for the management of breast cancer patients and should be addressed. Hospital administrations have an important role in improving some of the aspects referred, which should also be addressed by national policies and legislation, with the aim of improving the quality of life and care of people living with breast cancer in Portugal.

Conflict of Interest

None. ■

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