Temporality and timework: Danish endometrial cancer patients’ experiences of an accelerated cancer patient pathway

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Early diagnosis and rapid treatment are deemed essential in relation to cancer. In 2007, Denmark implemented accelerated cancer patient pathways (CPPs) with predetermined time frames to reduce waiting time. In this article, based on fieldwork with observations at two hospitals and ethnographic interviews, we examine temporal experiences of the CPP for endometrial cancer of the uterus at stage I. Results show that while the CPP helps suspend thoughts of death it also brings a sense of timely confusion and concerns about whether disease has spread. This ambivalence is linked to a political discourse of cancer in general as acute and a clinical, biomedical framing of endometrial cancer in particular as “good” due to its slow growth. We demonstrate how women customize their temporal experiences to accelerate or decelerate time and argue that waiting is not necessarily a passive state. We emphasize the need for professionals to be aware that CPP time and subjective patient time is not always synchronized.

**Keywords:** Inner time, Anthropology, Temporal dimensions, Time management, Fragmentation of time, Qualitative research, Waiting time, Endometrial cancer, Gynecological cancer
The experience of waiting when ill has become synonymous with anxiety, frustration, and distress (Carr et al. 2014; Sellerberg 2008; Ferrie & Wiseman 2019). Further, the rising worldwide cancer epidemic (WHO 2018) demands early and rapid diagnostics and reformulates cancer as an acute state. Cancer survival in Denmark has been lagging behind other Western countries for many years; thus, in 2007, “acute action” (The Danish Government 2007) was taken in the form of standardized cancer patient pathways (CPPs) to regulate cancer diagnostics and treatment with time as the structuring element. Based on the assumption that the faster the treatment the better, the objective is to minimize system delay and waiting time; thereby ensuring fast diagnosis and improving treatment and survival.

In this sense, standardization of cancer care appears beneficial because it supports the assumption that if disease is detected early and treatment started quickly, the patient will more likely survive. It is, however, difficult (if not impossible) to homogenize diagnostics and treatment for over 200 different cancers, especially since the speed of treatment of some cancers seems less important from a medical perspective. This is the case with endometrial cancer, which is typically portrayed as non-aggressive and slow growing. Even before the implementation of CPPs, endometrial cancer had a high 5-year survival of about 97% at stage I (Lajer et al. 2012:977) and research indicates that delay does not affect survival at stage I (e.g. Levy et al. 2006; Menczer 2000).

The implementation of CPPs introduces important considerations regarding patient experiences, which are particularly relevant with regard to a non-aggressive cancer; for example, how favorable prognoses affect patients’ comprehension and handling of the CPP. The CPPs are generally referred to as successful since waiting times are reduced (Probst et al. 2012) and survival seems to increase (Allemani et al. 2018). Nevertheless, we know little about how patient experiences are influenced by this reorganization of cancer treatment. Research on accelerated pathways primarily refers to clinical studies of immunological response, complication level, improved recovery, and effect on length of referral, treatment, and survival (Dahl et al. 2017). Only one evaluation of the Danish CPPs has been
conducted (Vinge et al. 2012), with a focus on organizational challenges and not patient perspectives. While the notion of time is considered biomedically important by being closely connected with survival, knowledge of how temporal structures within the CPP shape patients' clinical encounters and experiences is sparse (Håland & Melby 2017; Probst et al. 2012). Waiting in relation to illness has been given significant attention in the literature. However, the experiences of having endometrial cancer have not previously featured in discussions of waiting and time, and this article provides the opportunity to explore waiting in the specific context of CPPs and temporalities in conflict (cf. Bissell 2007).

The aim of this article is to explore how a group of Danish women with endometrial cancer at stage I, i.e. with favorable prognoses, experienced and perceived time within a standardized CPP and how it related to their experience of having cancer. Further, we illustrate and discuss how they acted with time within the structures of the CPP. Doing so, we aim to contribute to a better understanding of the temporal experiences of being a patient within standardized cancer treatment in Denmark; thereby providing relevant knowledge for future management and revision of CPPs and the patient-centered health care therein. Overall, the article adds to our understandings of waiting more generally by illustrating how times of waiting are not always passive, unproductive, or unwanted.

**Cancer patient pathways and endometrial cancer in Denmark**

In 2007, an initiative for improving cancer care in Denmark was taken when the Danish Government declared that cancer should be treated as an acute condition and decided to introduce national fast-track programs for all cancers as soon as possible. The message that “cancer detected in time can be cured” came to play a significant role, with delay introduced as a prominent campaign concept to promote the necessity of immediate action (Tørring 2014:20) and the notion that cancer should be perceived and treated more offensively; politically, medically, and personally.
Focusing on early diagnosis, some fundamental assumptions are rooted in the Danish CPPs. The CPPs combine bureaucracy, politics, technology, and biomedicine and build on coordinating, standardizing, and speeding up the process, focusing on the period from first referral to start of treatment as particularly important to clinical outcome (Vinge et al. 2012). In doing so, the CPPs reflect modern normative frameworks built around speed and productivity; “entrenched in Western individualist understandings of what is good and preferable” (Ferrie & Wiseman 2019:525; Zerubavel 1987; Bissell 2007). Patients are referred to a CPP, which describes the pathway from suspicion of cancer to diagnostic procedures and treatment through clinical guidelines of required medical procedures, organization of primary (GP) and secondary (hospital) sectors, and allocated timeframes of all phases—all steps are planned and booked in advance (The Danish Health Authority 2016). Compliance with timeframes are monitored to hold hospitals accountable for any delays. Timeframes vary slightly depending on cancer type and prognosis, but overall guidelines are more or less the same for all CPPs. Table 1 shows the CPP for endometrial cancer. Average length of the CPP for women in this study was 19 days.

Table 1: Endometrial cancer CPP

| From referral to start of diagnostic process | 6 calendar days |
| From start of diagnostic process to concluding diagnosis | 15 calendar days |
| From diagnosis to start of initial treatment | Surgery | 8 calendar days |
| From referral to start of initial treatment | 29 calendar days |

In Denmark, 95% of patients with endometrial cancer are 65-75 years and more than 80% are diagnosed at stage I, where prognoses are highly favorable as it is still encapsulated by the uterus. This provides good treatment options (Lajer et al. 2012). Treatment at this stage is a laparoscopic hysterectomy followed by intensive, early mobilization after which patients are discharged, usually the
same day of surgery. It is this specific group of patients with early stage cancer we address in the article and, thus, results should be seen in light of these favorable prognoses.

**METHODS AND ANALYSIS**

The article is based on an anthropological study of experiences with the CPP among Danish women with stage I endometrial cancer. Data were generated through fieldwork by Sidenius, September 2013–October 2014, with interviews and observations at two Danish hospitals. The dataset consists of transcripts and field notes.

We applied a technique of purposive sampling aimed at achieving a variation of age, education, employment and marital status among the participants, who were accessed through the hospitals. Secretaries helped identify relevant patients with an upcoming appointment at the cancer clinic. On the given day, the woman was asked by health professionals if Sidenius could attend her upcoming consultation. The woman and any accompanying relatives were always given time to consider the response. After the consultation, the woman was provided further information about the study and invited to partake in interviews. 18 women, age 48-81, were recruited.

Women who needed adjuvant therapy were excluded on the assumption that treatment type is central to the experience (e.g. von Gruenigen et al. 2006). All women gave written consent, and the study was approved by the Danish Data Protection Agency (12-000179). Further, oral consent was continuously affirmed.

Observations were conducted during endometrial cancer-related activities at the two hospitals. Sidenius sat in on consultations with gynecological examinations, disclosure of diagnosis, information about treatment, and pathological results after surgery; observed surgeries, hospitalizations, and discharges; accompanied women around the wards and spent time at the bed units or in waiting rooms.
Observations were documented through scratch notes that were elaborated into more comprehensive notes later that day. Observations made it possible to examine how women reacted to their situation and how meaning emerged from dialogue and interaction with health professionals. Moreover, they provided insight into the structural conditions, constraints, and challenges that professionals and patients encounter in the CPP and helped identify appropriate topics to be raised in individual ethnographic interviews. The women were interviewed 2-4 times in a 6-months period from their diagnosis to first follow-up consultation: A) 1-3 days before surgery, B) 1-2 weeks after surgery, and C) in relation to follow-up examinations 4-6 months after surgery. A question guide was developed with broad questions concerning the woman’s own review of her overall trajectory, her experience with the CPP, and questions regarding illness perceptions and personal experiences with cancer. Ongoing contact with the women and knowledge of their trajectory made it possible to individualize interviews, e.g. by following up on issues from previous conversations and clinical encounters. Conversations about cancer may be sensitive; therefore, relatives were welcomed into the interview if the woman wished so. All interviews were recorded and transcribed verbatim.

Based on ethnographic principles (Hammersley & Atkinson 1996[1983]), first step in the analytical process was reading the dataset repeatedly to gain familiarity and an overview. Readings were combined with open coding by Sidenius that involved line-by-line categorization of the material to identify all themes and ideas suggested by each line. From this, it became obvious that temporality was central, as the women repeatedly expressed issues of time in different contexts and forms and talked about their experiences in temporal terms. For example, they expressed gratitude for being “in time” or explained how they were unable to remember in what sequence specific activities had occurred. Overall, such expressions centered around two poles of temporal experience between which the women navigated: On one hand the women experienced time within the CPP as going “too fast”, while on the other hand they felt that the course of diagnosis and treatment was taking “a long time”.

These poles were related to a sense of duration, i.e. the perceived passage of time. Sidenius then coded data with a specific focus on the significance of time and contextuality of the two poles. Here, it became evident that women made great efforts to manipulate their experience of time within the CPP to either slow it down or speed it up, or, in other words, determine the allocation of time during their trajectory, for example by “taking time” for staying in bed.

**Theoretical framework**

Waiting exemplifies relations between time, power and agency, as time shapes our reality. A key strand of social research on time has argued that time in itself, however, cannot be retained and is basically nothing but a measure of something else; thus, the essence of time becomes central. Calendars and clocks are cultural constructs to keep track of time in the coordination of activities (Zerubavel 1987, Gell 1992) and, as argued by Mumford (1955 in Nicolaisen 2004) and others, the measurement of time can be seen as a prerequisite for the regulation of work and synchronization of production; thus, time in itself is a commodity not to be wasted. Within modernity, observing and adhering to time is an important skill, and if not respected often interpreted as a sign of sloppiness, indifference or lack of motivation. Time is a valuable scarcity that constrains us, creates possibilities and structures our everyday lives through frameworks of time, often involving periods of waiting characterized as “wasted time” (Ferrie & Wiseman 2019). We talk about unobservable conditions such as hours, days and months, making time measurable as well as objectifiable and calling for metaphors that suggest countability and value: spending time, time is running, not having enough time, time is money, time is precious. If time then is a scarce resource, the strategy is to figure out where and when to use time, whereby modernity has made way for the “exercise of power over other people’s time both on the side of the powerful […] and on the side of the ‘patient’ as they say in the medical universe, one of the sites par excellence of anxious, powerless waiting” (Bourdieu 2000 in Ferrie &
Wiseman 2019:523). Reduced and short waiting time denotes priority and signals importance and necessity, whereas long periods of waiting highlights structural effects and amplifies powerlessness among those waiting: being made to wait is often regarded as a symbolic display of degradation (Zerubavel 1987:345, Ferrie & Wiseman 2019:526).

While the rhythm of society emerges through an accrual of sequences, expressed in the clock as an external temporal framework enshrined in various institutions, individuals will however have subjective experiences of time; imbued with meaning. Such experiences are shaped by clock time and fixed time frames, but also of the content itself within these frames (a busy day of uninterrupted activity is, for example, different from a quiet day with much free time although clock time is exactly the same). A Schutzian perception of time as both outer and inner allows us to analytically separate the standardized temporal structures of the CPP from how the women experienced time while being subjected to such external organization. Drawing on Husserl and Heidegger, Schutz (2005) suggests that outer time concerns an objective time, where the temporal flux is divided into clearly distinguished segments. This is independent, unchangeable, infinite standard time and represent what Adam (2002) has called clock and calendar time, i.e. minutes, hours, days etc.. In contrast, inner time reflects subjective, personal, uncontrolled experiences, in which time is felt as unreflectedly intertwined and without chronology. We employ Schutz’ conceptualization of time to examine the different tempi and durations experienced by women in their encounter with the CPP and the waiting time herein.

Following Fujita (2002), waiting can be characterized by “how we wait” (Fujita 2002 in Ferrie & Wiseman 2019:522) and thereby also has the potential, as will be shown, to offer an opportunity for reflections, negotiations and production of social meaning. Emerging from our analysis are agentic practices that to some degree challenge common notions of waiting as a passive, powerless state; thereby supporting Bissell’s assertion that agency is embodied through the capacity to decide how waiting is done (Bissell 2007:285). Thus, we apply Flaherty’s (2011) concept of timework to examine
how the women responded to and navigated the CPP time structures by attempting to transform their experience of time. Timework refers to the intrapersonal folk theories and everyday practices by which we all strive to control the various dimensions of temporality and “bring into being circumstances that provoke the desired form of temporal experience” (Flaherty 2011:3). According to Flaherty, timework – as a capacity for selective attention – implies a degree of agency, meaning that individuals are able to focus attention on only a small part of their reality, interpret the situation, and choose between different responses within a given frame of structures (Flaherty 2011). Thereby, they intend a specific subjective experience of time to result from their conduct (Flaherty 2011:7). Thus, time is not just inflicted on us but results from efforts to generate and modify specific forms of temporal experiences.

Finally, we draw on Rotter’s (2016) account of deadlines. Since women in our study waited both for a final end to their illness trajectory (either cure, further treatment, or, ultimately, death) and for a range of specific events in the meantime (such as blood tests and consultations), instances of what Rotter calls short-term waiting (i.e. constant deadlines) punctuated their long-term waiting (Rotter 2016:85). Such deadlines, Rotter argues, act as promises of action by engendering an expectation of an outcome and are thus a point in the future to which the woman may orient and engage herself, for example by timework. Connecting timework with constant deadlines allows us to examine how the women sought to transform time between the present and that point in the future into graduating stages that brought them closer to the, hopefully positive, final end point.

RESULTS

In the following, experiences of the CPP are presented as two contradictory, but complementary poles in which time is experienced and managed differently. The women’s experiences were characterized by, on one hand, a sense that time was sometimes dragging by – this contributed to a need for a faster
course of events, making women try to accelerate time through maneuvers of timework. On the other hand, a sense that time passed by too fast was also present, as women were reassured that endometrial cancer grows slowly and is rather “peaceful” – this, in return, related to a need of slowing down time, as it was experienced as fragmented and de-chronological. We stress that this is an analytical distinction and do not assert that each woman was positioned in either one or the other pole—rather, there was a ceaseless flow back and forth, as women strived to balance the two. In the same situations and sentences women commonly articulated both poles: “It wasn’t something that was urgent as such; it just had to be done now!” (Miriam).

“*It should go fast*”: speeding up the process

The immediate responses to the CPP were positive among all the women. Most expected long periods of waiting as they entered the CPP but found that those expectations were wrong. The accelerated pace was seen as imperative, as most women saw a connection between time and survival and were keenly aware of the psychological consequences of waiting:

I don’t think it can go too fast when it’s [cancer]! You *want* it to go fast. Instead of waiting and thinking 'oh no, now it’s growing’, right? And ‘what will happen now?’ and…and all those thoughts. That's not good, no, three days was enough for me! […] You get to think *a lot* in three days! [Karen]

The excerpt illustrates variation in the perceived passage of time, both in terms of tempo and duration. While outer time (cf. Schutz 2005; Adam 2002) of the CPP continued according to standard temporal units of clocks and calendars, the woman above experienced inner time while waiting as prolonged, giving her time to speculate. The amount of time that seems to elapse during a given interval is governed by one’s circumstances: although the CPP seem rapid on paper it may still feel as slow given the specific context, in this case a framing of cancer as acute.
**Acute cancer: the faster the better**

Both women and health professionals believed that the duration and course of time related to the diagnostic process determine the quality of the surgical treatment; perhaps even more so after the implementation of CPPs. This way of looking at cancer was reflected at the clinics and in encounters between patients and health professionals. For example, doctors and nurses praised women for having reacted quickly to symptoms, which retrospectively was associated with having discovered the cancer “in time”. While the meaning of “being in time” was never specified, it seemed to be linked with cancer still being encapsulated in the uterus; that is, at an early stage. Within the structures of CPPs, health professionals found that a prerequisite for a rapid trajectory—and, consequently, survival—was that the patient had entered the pathway “in time”, i.e. contacted her GP as soon as symptoms appeared. Thus, the notion of being “in time” had a moral dimension to it, as it was linked to the idea that disease can be captured at a certain right time. This essentially relates back to the woman’s awareness and actions and places a personal responsibility upon women to be informed about cancer symptoms and present them in a timely way. This was often not the case: some women took post-menopausal bleeding as a stress symptom; some believed they had not fully reached menopause; and others wanted to wait and see if the bleeding worsened—actions that retrospectively were interpreted as “irresponsible” or “stupid” by either the woman herself, relatives or friends. Hence, the imposition of responsibility was a burden on some of the women.

For the participating women, survival was inevitably linked to the quickness of the diagnostic process. Reducing time from the onset of disease to diagnosis was believed to potentially postpone death: the faster the trajectory, the shorter the wait, the better the chances of survival. The risk of growth was deemed less likely if cancer was removed quickly:

If [cancer] started shortly before I discovered it, it's limited how much it has been able to
spread [...] and when treatment is fast, it’s also gone again fast! [Susanne]

Further, many women attempted to assess their chances of survival by locating the temporal origin of the disease and by doing so adhered to a linear understanding of time (Nicolaisen 2004; Gell 1992). This is reflected in the connection made above between the time from onset to diagnosis to treatment and the assumable “limited” extent of disease growth, where progression of disease is marked by time itself. While there is no predetermined sequence or course of tumor development (Tørring 2014:21), this connection is centered on a belief that the discovery of disease depicts a specific point on a natural, fixed line of development from normal to severely ill (and, ultimately, to death). Several women employed this rationale and attempted to retrospectively calculate a specific “starting time” by relating onset to past bodily sensations such as a stomach infection five years ago or an episode of neuritis.

Rotter claims that long-term waiting for a deadline is directed at something: the commencement of an event (e.g. surgery or a consultation), a change of circumstance (e.g. a diagnosis), the arrival of a particular state (e.g. relief or anxiety) or a physical object (e.g. scanning results), and this directedness may have a positive modality, directed at something which is longed for, or a negative modality, directed at something which is dreaded (Rotter 2016:85). Waiting may, however, also be directed at nothing in the sense that one does not have a clear endpoint, neither positive nor negative. This modality of waiting, where one does not know what to expect at all, can be far more unbearable than a waiting directed at something, which is dreaded for.

From the women’s accounts, it is clear that at the outset their long-term waiting was in its positive modality oriented towards the specific, clearly discerned goal of surviving. The acceleration of events of the CPP became central in enabling them to keep a focus on this modality. All women found consolation in the fact that they were promptly treated, as this enhanced the chances of survival being
realized—thereby, the hope associated with the likely positive outcome (leading the woman above to believe that “it’s also gone again fast”, like above) oriented them to a positive modality of waiting.

Despite such positive modality, focusing on early diagnosis and delay also suggests a strong connection between death and cancer if not acted upon immediately. Hence, the CPP conveys a strong message and an imperative for action by making cancer an acute disease. This is further enforced by the notion of being “in time”, which is implied below:

I guess that's why they've made these pathways [...] they have to fix it before it spreads [...] You need to get it fixed right here, right now! And they [doctors] must have some experience with that, since everything has to go this quickly. [Joan]

You wait and wait and wait and nothing happens—we hear such stories all the time [...] a woman should’ve been under surgery, but it took two months [...] and now it's too late! With me, everything went so fast; that's a sign that they dare not leave it there! [Emily]

Several aspects of these quotes are relevant. Firstly, “right now”, “dare not leave it”, and “before it spreads” emphasize that timing of detection is crucial within the predetermined course of progression—the notion of being “in time” also specifies a risk of being “too late”, as remarked in the second quote. This risk parallels the negative modality of waiting for something which is dreaded (Rotter 2016:85). The accounts indicate that the women speculate about what would have happened if their cancer had not been acted upon at this specific time. This is; however, a purely theoretical question and they can only speculate about the answer (or retrospectively rationalize). Hence, discourses on cancer as acute was implicitly strengthened by the CPP, as temporal dimensions attached meaning to the situation. The mere fact that CPPs are implemented to begin with indicates severity and thus strengthens the idea that cancer is always acute and deadly.
Accelerating time

All women described how, albeit in different ways, the fast pace of the CPP prevented or halted “negative thoughts”. Uncertainty about the future dominated their experience, especially when waiting for the diagnosis or the results of scans for possible metastases. Most thoughts and fears of worst-case scenarios arose in these periods. In these instances, as the women were wedged between the unfolding present and the future event, the women were waiting in a negative modality (Rotter 2016:81,85). They and their relatives reported that waiting for clarification was mentally exhausting:

It’s this…waiting! What will they tell you? It’s the waiting that’s causing you to toss and turn at night and be very tired […] but the uncertainty wasn’t there for long because it all went so fast; everything’s uncertain until you get the diagnosis. We didn’t have time to get a lot of…wrong thoughts, right? [Tom, Ann’s husband]

Especially the wait between the scan and answers was bad…I worked 120 km/hour every day not to think about it. It's the waiting that's long; there’s really time to fantasize! [Charlotte]

The physical restlessness (tossing and turning), felt by Tom, arguably relates to the feeling of suspension of movement in time in which “nothing happens”, as mentioned in an earlier quote. In asking “what will they tell you?” Tom points to the essence of waiting for something to (or not to) occur or arrive. In this sense, change has a direction forward as there is a kind of linear movement, whereas a lack of movement is experienced when waiting for a “long” time: time stands still or moves slowly. As a response, many women tried to accelerate time and make it move faster. Especially the period from diagnosis to surgery was subjected to temporal creativity – i.e. timework – as women kept themselves busy or filled the time with pleasurable activities and company. Below, Susanne describes how she immersed herself in her work as a school principal. Immediately after receiving the diagnosis, she started preparing for Christmas and planning an upcoming Saint Lucy’s Day parade:
I went directly [from the hospital] to the school and said to my husband: ‘We have to buy Poinsettias now! Have you remembered this and that and this?’ and I went to my email and sent the [parade] invitation and thought to myself ‘we also need to take care of this and that’ and in the hallways I started hanging up the decorations and the elves. [Susanne]

Other examples of filling time are cleaning the house, fixing the garden, organizing the attic, organizing personal documents, booking meetings in the bank, cooking and baking, gathering information about endometrial cancer or surgery, spending extra time with family and friends, updating insurances, and creating a will. Such lines of activity were both future-focused in addressing the risk of death (e.g. the settling of bank accounts) and present-focused in providing meaning to everyday life (daily procedures such as cleaning) (Rotter 2016:82). Hence, waiting served as an incentive to attempt to maintain ordinary life by integrating the wait in trivial routines.

The significance of deadlines

Women referred to the hospital in a CPP must wait for both a series of specific events within the pathway (blood samples, consultations, or results of a test) and the final end of the process. Many described in distress how the time between the CT scan and getting the results was unbearable because this event was a turning point in their trajectory—both because they perceived the results as correlated with chances of survival, but also because the results would lead to the kind of necessary action that up until then was impossible to undertake. The test results determine possible treatment, but each result was also a specific event that must be transgressed to move forward. Once a woman received the date of the consultation regarding these results (once a deadline was specified), she could transform time between the present and that specific consultation from undetermined, immeasurable waiting into a stage of activities that serve as markers of time (Rotter 2016:90). Doing so, the woman gained the possibility of locating herself in relation to her future and of asking a very central question:
am I getting closer to a, hopefully, happy ending? For each stage she could put behind her, the impression arose that she was—albeit gradually—approaching the endpoint of her trajectory. Consequently, the period of each stage seemed both controlled and limited: “The waiting and the uncertainty wasn’t that long. That's nice because what would you fill time with?” (Rose). Such positioning in relation to the future was expressed as taking the process “step by step” or “one day at a time”, each step signifying an increased temporal proximity to the future. “Time-reckoning” (Gell 1992) or calculation of “clock duration” (Adam 2002) (i.e. how much time has passed during this activity) allows the woman to estimate at what rate she is moving forward towards the object of her waiting. In this sense, waiting also has its own temporality in terms of tempo, i.e. the flow and speed of time.

The CPPs pre-arranged timeframes were essential to patients’ high satisfaction with the CPP. Waiting became tangible due to such specific, well-defined objects of waiting:

> We were basically told: ‘Don’t worry about anything—we'll fix it’! You just show up; it's amazing! There’s someone taking care of everything all the time; you don’t go home waiting for a call—you always have a date! When you leave, you get a new date. You’re not left to yourself and a phone call or a letter that they forget [...] You’re in good hands…right from the start [...] That’s important; that someone is controlling things...for you, because you cannot do it yourself [Annett]

Besides pointing to the comforting fact that the woman is exempted from responsibility, the feeling of “always having a date” added a sense of confidence that the process was under control and progressing. While cancer on one hand is framed in public popular discourses as cells out of control (suggesting that the disease can basically not be controlled), action-oriented activities such as the massive amount of tasks during consultations and especially the planning of time within the CPP on the other hand represents ways to deal with the disease and symbolize that action is taken although
such activities imply a degree of control that in reality is not possible. The specific dates indicated a linear movement in which the patient was constantly approaching the endpoint. Thus, while the pathway was characterized as an intense experience with a comprehensive range of activities compressed within a short period of time, most women appreciated this high intensity, because they always knew exactly what short-term intervals of time to fill out and felt that the experience of time passing slowly would be worse. Many women’s experiences of time thus reflect the circumstances of the CPP; however, it also intertwined with the way they wished time should pass:

It doesn’t matter that things go fast ‘cause you can hardly cope with anything else than the fact that you’re ill. If you got the diagnosis and no one did anything; that would’ve been horrible! [Sandra]

Our participants stressed how deadlines implied an imperative of action and thus a change in the situation. As pointed out above, it would have been neither sufficient nor very satisfying to receive a diagnosis if action was not taken subsequently. Hereby the length of the waiting time would be undefined and thus given a sort of “open-endedness” (Brekke 2004:23) or non-linear movement. The institutional planning of the CPP is then framed as a resource, presuming a particular temporality: the planning of cancer treatment is related to the hope of surviving. Thus, the predictability of the pathway’s temporal framework with its fixed time, position and role is paradoxically closely connected with the future; that is, the ultimately unpredictable.

“Things are going too fast”: compression of time

Despite uttering great gratitude for the pace of the CPP, numerous women sensed that the overwhelmingly condensed pathway went “a little too fast”. Frequently, the CPP was compared with being on a
train or train station. Employing factory metaphors was also common, as in the following field note from a consultation two weeks after Sandra’s surgery:

‘It’s bang-bang-bang’, the woman said and illustrated by banging her hand on the table. She went on: ‘You come in and you come out—you’re on an assembly line, for God’s sake! They take your uterus and then they take my uterus; then we’re put to bed, and then we’re out! We go home and a new group [of patients] arrives! And then they go home!’ [Sandra]

Several aspects are important here. First is the questioning of the design of the CPP by referring to factories, which the women characterized by people moving from A to B, constant arrivals and departures, and the feeling of being rushed and stressed—unpleasant emotions experienced by all the women. Second, by paralleling the CPP to assembly lines, women critically addressed the fact that the circumstances of CPPs do not leave much room for personal preferences or for taking care of the individual woman. It is a prerequisite for consistent, efficient workflow and compliance with the outlined timeframes – i.e. outer time – that the woman rather uncritically accepts the prearranged and routinized appointments and adapts inner time accordingly. In essence, this strips the women of autonomy and individuality. Finally, an assembly line not only expresses relations of time in which time is thought of as having a direction forwards—towards something in a linear, steady, and unstoppable manner—but also the notion that things must go fast; that as much as possible should be done in the shortest time. However, as we will show below, this notion of haste did not always fit with having endometrial cancer.

*Endometrial cancer: slow and peaceful*

Because of its favorable prognoses, doctors and nurses portrayed endometrial cancer as a so-called “good cancer”. Women were reassured that it “grows slowly” (doctor), is “harmless” and “peaceful” (nurse), that the uterus reduces risk of disease growth by encapsulating it, and that if health
professionals themselves “had to choose a cancer, it would be this one” (doctor). This framing of endometrial cancer positioned the women as being in a particularly optimistic situation; that is, waiting in a positive modality, where a degree of silencing of adverse effects of, for example, surgery implied that a positive outcome was almost certain. Gradually, the women adopted this optimism, which was reflected in their interpretation of the situation: “The doctor said it was nothing to worry about; they don’t consider it something special” (Mary). Accordingly, most women got the impression that treatment did not need to take place immediately: “It doesn’t have to go fast. Take it eeeeasy” (Lisa). However, the framing of endometrial cancer as slow and “good” also stood in stark contrast to the hastiness of the CPP and thus generated bewilderment and concern among several women. The speeding up of activities gave rise to speculations about whether the disease was in fact more alarming than doctors had indicated:

For a while I thought: ‘Hey! Is it [i.e. cancer] very advanced since things are going so fast?’ It must be serious, right? But afterwards I’m glad that it went fast… [Ingrid]

It’s two-sided. Firstly, it’s damn great that things go fast when it’s cancer and, secondly, when things go this fast is it actually because it’s really critical? [Lisa]

These excerpts address the fact that while the women tried to maneuver within the time structures of the CPP they also navigated another form of temporality, where some cancers were understood to be aggressive and fast growing and others were not. Hence, the notion that a particular temporality was associated with the disease, namely that endometrial cancer was a “slow-developing cancer type” (doctor), played a significant role in the anxieties that arose among women, who started wondering why things needed to speed up. Though probably intended to calm the women and instill hope, the particular way of speaking of endometrial cancer as slow, peaceful, and with good prognoses thus
sometimes turned out to be counterproductive within the institutional and temporal structures of the CPP.

*Fragmented time*

When accounting for their trajectories, most women were unable to separate various consultations, conversations, and examinations from each other. They were confused about information and specific dates and sequences, tended to switch the order of certain occurrences and activities around, forgot significant events and details, or asked Sidenius to specify or confirm when, where and for how long a particular incident took place. When Sidenius asked Ann and her husband Tom what happened after surgery they both struggled with reconstructing the process:

*Ann:* Well, I came home...Thursday...yes, and so -
*Tom:* [interrupts] - no, you came home Friday!
*Ann:* Was it Friday?
*Tom:* Yes...I think so. You went to the hospital Thursday and came back Friday.
*Ann:* Oh...oh, well [pauses for a while] ...okay...And then I guess it was...uuhh, Monday or Tuesday...Monday? Everything blends together...
*Tom:* Hmm...no, I think it was Tuesday?
*Ann:* [local hospital] called, yes...and then Tuesday they [the specialized hospital] called -
*Tom:* [interrupts] – wasn’t it? Uuuh...is that how it was?
*Ann:* Yes...or how was it now? Was it actually Wednesday they called from [the specialized hospital]? [They both pause to think for a bit]
*Tom:* Yes, that might be...
*Ann:* No, I think it was Monday they called from [the local hospital]... right?
*Tom:* Yes, ’cause that’s when we were in the summer cottage, right? With Lisa and Mark...
*Ann:* Yes...that’s right.
Tom: But perhaps the call was from [the specialized hospital]?

Besides exemplifying the rather inconsistent, fumbling time experience held by many women, the conversation above also reveals how the women and their relatives sought to fit their inner time experience with outer time. While calendars are culturally constructed tools of keeping track of time, the idea that they measure some sort of ontologically existing time blurs the social background for the understanding of time, giving time a state of naturalness (Gell 1992). Hence, through several types of timework the women frequently sought to transform the distorted feeling of time into something that was thought of as more coherent by re-contextualizing inner time in accordance with outer time, for example by establishing time of phone calls in relation to a trip to the cottage as illustrated above. As such, Ann and her husband constructed a spatialized, shared time in their life with others, although inner time essentially is without such spatial elements (Schutz 2005). Constituting their narrative in a linear temporal order that emphasizes continuity contributed to a sense of coherence and gave logical order to events that were otherwise experienced as chaotic.

Another aspect of the fragmentation of time was a connection between the description of time passing by too fast with the body or bodily sensations or acts. Patient expressions like “I feel a little batty”, “you get totally dizzy”, “you feel quite light-headed”, “my head is spinning”, “I have to lay down for a bit”, “they’re running around”, and “I have so many things in my head” communicate and symbolize this time experience. The linking of rapidity and busyness to the feeling of “having many things in the head” suggests that the amount of events or activities is important to the experience of time in itself, but particularly in relation to the act of mastering them (Lidén 2004:73). The women must, for example, engage in a wide range of activities to prepare for surgery. They are scheduled for blood samples and ECG; a consultation with an anesthetist (whom they must inform about current medicines); and a talk about the hospital admission with a nurse. During this latter conversation, oxygen saturation, blood pressure, pulse, temperature, BMI, social relations, medicine usage, functionality
prior to surgery, respiration and circulation, and activity and mobility capability is registered in the medical record. Further, the women are given premedication, informed about meeting time and place before surgery, have support stockings measured, and are shown around the bed unit. On the evening before surgery, they must take a strong laxative; shave their pubic hair; clean the belly button; shower and wash their hair; and swallow two different antacid pills. Finally, on the day of surgery, they fast from 05:00 A.M.; take painkillers, antibiotics, and another laxative; and make sure to go to the toilet just before they are taken to the operating room. The women must remember both to complete all these activities and to do it in the correct order to be effective. The awareness of having to concentrate on doing something at certain intervals and sequences, and doing it effectively to ensure successful treatment and, ultimately, survival generates the experience of things having to go fast. Thus, the sense of confusion can be understood as linked to the fact that for some women it is demanding to relate to all of these things at the same time; after all, they are not internalized as automatic practices.

The expectation to master different activities also involved a requirement of bodily control. Parts of the body became the centre of attention. Within the CPP, patient mobilization takes place within hours after surgery, and duration out of bed is registered. As soon as urination is completed, the patient is usually discharged. Thus, attempts at bodily control—for example by opposing the body’s signal of staying in bed due to pain or nausea—becomes part of the experience of things going too fast. This is, for instance, illustrated by the wish held by several women to stay one more night at the hospital (all rejected, except one); the need for immediate bodily tranquility after being discharged (often remedied by lying still in bed or doing absolutely nothing); and the fact that many women stayed in bed for days after returning home although this overrode professional advice. This may be associated with not being committed to bodily control but rather following one’s own rhythm and stopping time for a little while. The rapid rate and intensity of the CPP can thus be seen as central
factors that contributed to a disorientated, non-chronological experience of time, which did not correspond to the external and linear time structures of the CPP.

*Decelerating time*

While sensing an abrupt, complicated, and disharmonious structure of time rather than a chronological, predictable time; several women described their trajectories as confluent with a fusing of elements that made them feel that time passed too fast. The women sensed that they lacked time to keep track of events and activities, and, hence, time became scarce in both symbolic and concrete terms. Attempting to handle this, several made lists, timetables, and overviews of important dates, activities, and their overall path through the health system. Some brought these items along for consultations and interviews; others simply mentioned them:

> How was it? Hmm, I've written it down on a note ‘cause otherwise I can’t remember! It went so fast […] I've tried to write down whenever I got a date [at the hospital] and what I was supposed to do and when—otherwise I couldn’t find my way around it! [Charlotte]

Experiencing the CPP apparently gave rise to a need of trying to maneuver in the trajectory and create an outline of specific events; that is, make use of timework. Paradoxically, this meant that at the same time as many women tried to accelerate time they also attempted to make it pass slower—while they on one hand tried to distract themselves by filling the freezer with casseroles and weeding the garden, they sometimes also paid all of their attention to time via detailed schemes. A fundamental principle of the many strategies used within timework is, according to Flaherty, that the “perceived passage of time slows if you pay attention to time itself” (Flaherty 2011:16). Thus, the writing down of lists and timetables can be seen as attempting to control time in a need to chronologize and establish order in and of time and of the specific trajectory. In this sense, the temporal experience is decelerated because this sort of timework engenders an awareness of the details by (visually) placing events that are
experienced as overlapping and intertwined in chronological sequence to each other (Flaherty 2011:30-35). The course of time thus seems protracted and expanded instead of collapsed. Time literally stands still on a piece of paper. Another example is the following description of Miriam’s entry into the CPP:

I went to the doctor on Monday…and he sent an email to the gynecologist, who said that I should meet the next day; Tuesday that is […] And then the gynecologist sent for the hospital, and I went there for an examination two days later, it was on the 25th […] It was a Friday and on Tuesday morning the doctor called from the hospital to schedule a consultation. He said: ‘It's either today or on Thursday’, so I asked: ‘At what time today?’ – ‘Five minutes past 2 pm’, he said. […] And then I got the message that it was cancer and had to go to an X-ray, which was on Wednesday…I had to be there at 7:30. [Miriam]

By emphasizing the continuance in a constant course of action, the woman pays immense attention to precise points in time and relates her narration to outer time. This indicates that outer timeframes may function as symbols of action by illustrating the switches between different acts. Consequently, the establishment of exact timelines creates a sense of timing by the act of relating and coordinating specific activities to each other; hereby, the biography of the woman is unfolded (Schutz 2005; Rasmussen & Elverdam 2007:618). In return, this may produce the sense of coherence, linearity, and synchronization between inner subjective experiences of time and outer standardized clock time that many women sometimes felt absent in their experience of the pathway.

DISCUSSION AND CONCLUSIONS

This article shows how a group of Danish women experienced and dealt with time within a CPP and how this relates to their experiences of having endometrial cancer. The women navigated between certain interrelated contexts that informed their experiences: on one hand the construction of cancer
in general as requiring acute action and a sense that time passed too slow when waiting, and on the other hand an understanding that endometrial cancer specifically does not require immediate action and a sense that time passed by too fast due to the CPPs temporal compression. Experiences were largely characterized by ambivalence, as women lacked time while also having a surplus of time—time was precious and had to be maintained, but also a void to be filled, as it was set outside “normal” time. Across two such very different positions, we found that they both accumulated a need to try to control the experience of time; hence, time both caused temporal disorder and was a tool for establishing order.

In a Western context, waiting is commonly reduced to the mere passing of time and conceptualized as an undesirable, unproductive waste caused by the related state of dependency (Rotter 2016:87; Sellerberg 2008). Caught in time, the waiting individual is believed to be passive; lacking capacity to change the situation: “waiting can lead to paralysis […] the present loses its focus in the now” (Crapanzano 1986:45)—hence, the only meaning lies in the future.

Our results critically question such notions of waiting. If outer circumstances simply determine one’s experience of time, intervals of waiting would always seem to pass slowly. While the women did indeed articulate a sense of passivity and of being subjected to externally executed time structures of the CPP, the planned course of the CPP also became a source of trust and certainty in a vulnerable situation. Further, the women challenged the notion of waiting as inactive by making efforts to shape and negotiate their own sense of time. By considering what kind of temporal experience they wished to have, the women arranged circumstances such that they acted back on them with the desired temporal effect (Flaherty 2011:8). While the arrival of the next consultation was beyond the women’s control—just as cancer itself—they acted within given institutional frames to control their sense of duration and release themselves from the burden of waiting (Rotter 2016:15-17). Thereby, the women gained a sense of what Flaherty conceptualizes as “temporal autonomy” (Flaherty 2011:3). Staying
in bed all day, which is against the recommendations of rapid mobilization, is for example an implicit questioning of external constraints “directed at resistance to the effort of others to impose themselves on the experience of time” (Flaherty 2011:2); a questioning that also challenges images of the 'good patient' as one who restores to health with haste in order to be productive and legitimate and does not place undue pressures on the healthcare system (Jutel 2009 & Parsons 1951 in Ferrie & Wiseman 2019).

In contrast to widespread conceptualizations of waiting as problematic and useless, leading to frustration, anxiety, and passivity in a lack of alternatives (Carr et al. 2014; Sellerberg 2008), our results show that waiting time may also offer opportunity for agency, reflection, and relative productivity. This is in line with, for instance, Ferrie & Wiseman (2019), who illustrate how a series of agentic practices by people with terminal illness challenge notions of waiting as passive, universal and non-productive. When subordinated to temporal structures, women in our study tried to find a way, an alternative, to act for themselves by negotiating and incorporating waiting time into everyday life instead of simply taking place in suspended, outer time. The actions women employed when stocking their freezer before undergoing surgery, organizing a Christmas parade, or spending as much time as possible with family, were kind of preparatory for the possibility of becoming seriously ill or not surviving. Therefore, these activities manifested a productive kind of waiting (Rotter 2016:95), where social meaning was created by virtue of its potentiality. Timework is thus a social practice that challenges and is challenged by the temporal structures of the CPP, which essentially entails that time is not deterministic, but reflects both outer circumstances and personal negotiations within different structural contexts of behavior.

The women were highly grateful for the fast pace of the CPP. However, the Danish health care system in a way reinforces ambivalence, because the pathway also gives rise to a number of unintended and unfortunate dilemmas besides meeting its purpose of reducing waiting time. Hence, chronological
duration is not necessarily the most relevant consideration in determining the quality of the women’s waiting experience (Carr et al. 2014:1673; Barak & Leichtentritt 2014). The question is, of course, whether fragmented time is specifically related to treatment within a CPP or a matter of being diagnosed with cancer per se? Several studies have shown a general sense of confusion and uncertainty among cancer patients, but while our study is not able to answer the question—and is not intended to do so—our results definitely seem to illustrate that the CPP reinforces notions of time as a scarce resource that needs to be managed well, thereby reproducing uncertainties and notions of fragmentation, alongside more common feelings of anxiety, thoughts of death, and the need for information and control, which are equally important—albeit interrelated—elements of uncertainty as time is.

Results from this article outline necessary and important nuances to the meaning of accelerated and standardized treatment processes for the individual and the social aspects hereof. The study suggests that health professionals should be aware of time as central in comprehending cancer patients’ experiences, recognize that CPP time and patient time is not always synchronized and mobilize this knowledge in consultations with patients. Understanding how patients perceive and manage time and that experiences of time reflect both circumstances and wishes—and therefore contain an element of intentionality—is vital in providing deeper insight into possible reactions to the CPP, thus enabling more appropriate, contextual and sensitive care in situations, where external requirements must be fulfilled. Such knowledge may benefit patients by personalizing trajectories to accommodate individual circumstances, needs, and experiences of duration, and making sure that patients and relatives feel they are able to keep up, for example by allowing more room for adjusting the time of discharge to the individual’s time experience whenever possible and relevant; although quick mobilization after surgery reduces complications, something else is also at stake for the women in this study. With the CPPs as an excellent example, time management often focuses on clock and calendar time; however, as contributed by this article, time structures are not deterministic, and it is recommended to optimize
patients’ subjective experiences of duration at the hospital. It is, for example, important to provide patients with realistic estimates of how long they can expect to wait, as violations of these expectations (the sense that waiting is taking longer than it should) predisposes patients to the experience of protracted duration. Hospitality from the staff when arriving may also divert attention from consciousness of time, while physical overviews of relevant dates, times, and places may be useful combined with proactively engaging patients during clinical encounters in activities that require their attention and concentration, e.g. showing them their medical notes. Further, professional support is central to the articulation of experiences, which may enhance ongoing processing of the situation and diagnosis. Future research should explore implications for relations between patient and relatives, as the CPPs place great requirements to mobilize social networks (e.g. driving to/from the hospital and helping to manage upcoming appointments). Not all patients may be able to do so, and attention should be paid to whether CPPs unintentionally increase social inequality in health with resource-poor patients lagging behind. Finally, it would be of great importance to examine the senses of time within a CPP among later and more aggressive stage endometrial cancer patients as well as healthcare personnel.

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1 Additional cancer treatment given after the primary treatment to lower the risk that the cancer will come back. Adjuvant therapy may include chemotherapy, radiation therapy, hormone therapy, targeted therapy, or biological therapy.