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EXPERIENCE SAMPLING METHODS IN ADVANCED CANCER

UNCOVERING SYMPTOMS AND WELL-BEING IN DAILY LIFE

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Introduction

Oncology has traditionally relied on retrospective self-report questionnaires to assess symptoms and well-being. While valuable, this method is prone to memory effects and cannot capture how experiences unfold in real-time. Experience sampling methods (ESM), repeatedly prompting individuals to complete self-report assessments across the day, can address this gap, but their use in advanced cancer has been limited.

Objectives

This dissertation aimed to uncover the potential of ESM for understanding symptoms and well-being of people with advanced cancer, by addressing three aims: (1) adapt and validate ESM for people with advanced breast or lung cancer; (2) evaluate the feasibility, acceptability, and ability of ESM to capture symptoms and well-being fluctuations; (3) evaluate ESM's clinical utility in oncology practice from healthcare professionals' perspectives.

Methods

For Aim 1, I conducted a scoping review of studies that used intensive longitudinal methods among people with breast or lung cancer and conducted semi-structured interviews with people with advanced cancer and healthcare professionals to develop a content-valid ESM questionnaire. For Aim 2, I drafted a research protocol, conducted a pilot and final observational ESM study, and compared ESM responses with retrospective questionnaire responses. Participants received 10 ESM prompts per day for 6 days. For Aim 3, I interviewed oncology healthcare professionals on the clinical utility of ESM.

Results

The scoping review included 52 articles. Studies in people with advanced cancer were scarce, did not use intensive assessment schedules, varied widely in their used methodologies, and often had incomplete reporting. To develop the ESM questionnaire, 43 patients and 8 oncology healthcare professionals participated in interviews, resulting in a smartphone-based questionnaire with core and supplementary items covering physical, psychological, social, and existential experiences, alongside everyday contexts. The observational ESM studies (N=12, N=40) showed good completion rates (80%) and low burden across all ages. Symptoms and well-being fluctuated considerably within and across days. ESM and retrospective questionnaire scores correlated (ranging between .24 and

.70), but structural differences emerged, especially for pain (*Mdiff* = -13.2; 0-100 scales) and tiredness (*Mdiff* = -12.4). Differences were linked to, among others, symptom variability (B = 1.08, p < 0.001) and treatment status (B = 5.89, p = .010). Twelve oncology professionals highlighted potential benefits of ESM, such as providing unique insights into patients' needs and enabling real-time interventions. However, they also raised concerns, such as burden, added workload, and unclear added value.

Conclusion

ESM proved feasible and acceptable for use by people with advanced cancer, effectively capturing individuals' unique symptom and well-being fluctuations in daily life. The methods are a promising avenue to enhance personalized care and improve quality of life by revealing the mechanisms behind individuals' fluctuations and allowing real-time interventions.

Samenvatting

Introductie

In de oncologie wordt er traditioneel gebruikgemaakt van retrospectieve zelfrapportagevragenlijsten om symptomen en welzijn te meten. Hoewel deze aanpak waardevol is, is deze methode gevoelig voor geheugeneffecten en kan het niet vastleggen hoe ervaringen zich in het moment ontwikkelen. *Experience sampling* methodes (ESM), waarbij individuen meerdere keren per dag worden gevraagd om een korte vragenlijst in te vullen, kunnen dit tekort vullen. Tot nu toe is het gebruik ervan bij mensen met gevorderde kanker echter beperkt gebleven.

Doelstellingen

Dit proefschrift had als doel om het potentieel van ESM te onderzoeken voor het begrijpen van symptomen en welzijn van mensen met gevorderde kanker, door zich toe te spitsen op drie doelstellingen: (1) ESM aanpassen en valideren voor mensen met gevorderde borst- of longkanker; (2) de haalbaarheid, aanvaardbaarheid en capabiliteit van ESM evalueren om fluctuaties in symptomen en welzijn vast te leggen; (3) de klinische bruikbaarheid van ESM in de oncologische praktijk beoordelen vanuit het perspectief van professionele zorgverleners.

Methoden

Voor Doelstelling 1 voerde ik een *scoping review* uit van studies die intensieve longitudinale methoden gebruikten bij mensen met borst- of longkanker. Daarnaast ontwikkelde ik een inhoudsvalide ESM-vragenlijst op basis van semigestructureerde interviews met mensen met gevorderde kanker en professionele zorgverleners. Voor Doelstelling 2 stelde ik een onderzoeksprotocol op, voerde ik een piloot- en finale observationele ESM-studie uit, en vergeleek ik ESM-responses met die op een retrospectieve vragenlijsten. Deelnemers ontvingen gedurende 6 dagen 10 ESM-signalen per dag. Voor Doelstelling 3 interviewde ik professionele zorgverleners tewerkgesteld in de oncologie over de klinische bruikbaarheid van ESM.

Resultaten

De scoping review includeerde 52 artikelen. Studies waren in beperkte mate uitgevoerd bij mensen met gevorderde kanker, gebruikten geen intensieve meetschema's, verschilden sterk in methodologie en waren vaak onvolledige gerapporteerd. Voor de ontwikkeling van de ESM-vragenlijst namen 43 patiënten en 8 oncologische zorgprofessionals deel aan

interviews. Dit resulteerde in een smartphone vragenlijst met hoofd- en aanvullende items over fysieke, psychologische, sociale en existentiële ervaringen, evenals alledaagse contexten. De observationele ESM studies (N=12, N=40) hadden goede invulpercentages (80%) en een lage belasting, ongeacht leeftijd. Symptomen en welzijn fluctueerden aanzienlijk binnen en tussen dagen. ESM- en retrospectieve scores correleerden (r = .24 – .70), maar vertoonden structurele verschillen, vooral voor pijn (*Mverschil* = -13,2; 0–100 schaal) en vermoeidheid (*Mverschil* = -12,4). Deze structurele verschillen hingen samen met o.a. symptoomvariabiliteit (B = 1,08, p < 0,001) en behandelstatus van de deelnemer (B = 5,89, p = .010). Twaalf oncologische zorgverleners benoemden verscheidene mogelijke voordelen van ESM in de oncologische praktijk, zoals het verschaffen van unieke inzichten in de behoeften van patiënten en het mogelijk maken van *real-time* interventies. Maar ze maakten zich ook zorgen over verschillende aspecten van het gebruik van ESM, bijvoorbeeld over de mogelijke belasting van de patiënt, extra werkdruk en de meerwaarde ervan.

Conclusie

ESM bleek haalbaar en acceptabel voor gebruik door mensen met gevorderde kanker, en was capabel om fluctuaties in symptomen en welzijn in het dagelijks leven vast te leggen. Deze methode biedt een veelbelovende manier om gepersonaliseerde zorg te verbeteren en de kwaliteit van leven te verhogen door de mechanismen achter fluctuaties zichtbaar te maken en real-time interventies mogelijk te maken.

Non-academic summary

People with advanced cancer, in which cancer that has spread to different parts of the body, often experience many difficult symptoms that affect their daily lives and overall well-being. To better understand what they go through and how to best support them, researchers need ways to capture such experiences as they unfold in daily life.

One such way is a research method called the experience sampling method. With the experience sampling method, people use smartphones to answer a few quick questions about their current symptoms and well-being several times per day. Unlike traditional surveys, which usually ask people to remember how they felt over the past week, the experience sampling method can show how things change from moment to moment everyday life.

The research described in this thesis was focused on adapting the experience sampling method for people with advanced cancer and evaluating its use. This was achieved by following multiple steps in the form of separate research studies.

First, I looked in the existing scientific literature that had used methods similar to the experience sampling method in people with breast or lung cancer. The number of studies that used such methods among people with cancer was increasing, but remained limited in people with advanced cancer. Then, I developed a symptom and well-being questionnaire specifically for use in experience sampling studies (which was used in the later step of this research). Questions pertained to physical, psychological, social, and existential experiences, alongside what the participant was doing or with whom they were. Afterwards, I planned the following studies of the broader research project and described them in a scientific article. I then conducted an experience sampling study with a small group of people with advanced cancer to test if it is possible and not too burdensome for these people to answer multiple questionnaires per day. For 6 consecutive days, participants received 10 signals per day to complete the questionnaire. Because the study was possible and not burdensome for this small group of participants, I repeated the study in a larger group and found the same positive results. Additionally, the results showed that the experience sampling method picked up considerable ups and downs in symptoms and well-being that traditional surveys missed. At last, I conducted interviews with healthcare professionals in oncology, including oncologists, psychologists, and nurses, to explore if they think that the experience sampling method could also have value in in clinical practice. Healthcare professionals saw real value in using the experience sampling method in practice. It could help them spot patients' needs more quickly and provide timely, personalized care. But, they also shared many concerns that need to be addressed before the method can be effectively used in practice.

Overall, this work shows that ESM is both possible and useful for people with advanced cancer. It opens the door for future studies to explore what drives daily changes and how this approach might be built into routine cancer care.

Niet-academische samenvatting

Mensen met gevorderde kanker, waarbij de kanker is verspreid naar verschillende delen van het lichaam, ervaren vaak moeilijke symptomen dat hun dagelijks leven en welzijn aantast. Onderzoekers hebben manieren nodig om vast te leggen hoe zulke ervaringen zich ontwikkelen in het dagelijks leven, om zo de problemen beter te begrijpen en te behandelen.

Één mogelijke manier is een onderzoeksmethode genaamd de *experience sampling* methode. Bij het gebruik van de experience sampling methode antwoorden mensen typisch via een smartphone meerdere keren per dag op enkele snelle vraagjes over hun huidige symptomen en welzijn. In tegenstelling tot traditionele vragenlijsten, die gewoonlijk aan mensen vragen om hun te herinneren hoe ze zich voelden overheen de afgelopen week, biedt de experience sampling methode de mogelijkheid om te bestuderen hoe ervaringen in het dagelijks leven van moment tot moment veranderen.

Het onderzoek dat omschreven staat in deze thesis focuste zich op het aanpassen van deze methode voor het gebruik door mensen met gevorderde kanker en het evalueren van het gebruik hiervan. Dit werd bereikt door meerdere tussenstappen te volgen in de vorm van verschillende wetenschappelijke studies.

Eerst ben ik in de wetenschappelijke literatuur gaan kijken naar studies die de experience sampling methode of gelijkaardige methodes gebruiken bij mensen met borst- of longkanker. Er was een stijging in het aantal studies dat deze methode gebruikte bij mensen met kanker, maar bij mensen met gevorderde kanker bleef het gebruik ervan beperkt. Daarna heb ik specifiek voor experience sampling studies een vragenlijst ontwikkeld die symptomen en welzijn in het moment meet. Vragen gingen over fysieke, psychologische, sociale, en existentiële ervaringen, alsook wat de participant aan het doen was en met wie ze was. Vervolgens plande ik de hierna beschreven studies van het onderzoeksproject en schreef ik dit uit tot een wetenschappelijk artikel. Daarna heb ik een kleine groep van mensen met gevorderde borst- of longkanker gevolgd aan de hand van de experience sampling methode om te kijken of het afnemen van de herhaalde vragenlijsten mogelijk en niet te belastend was. Voor 6 opeenvolgende dagen ontvingen participanten 10 signalen per dag met de instructie om de vragenlijst in te vullen. Omdat de studie voor deze kleine groep van participanten haalbaar en niet te belastend was voor heb ik deze herhaald in een grotere groep waarbij we dezelfde positieve bevindingen verkregen. Daarbovenop toonden de resultaten dat de experience sampling methode heel wat schommelingen in symptomen en welzijn van mensen kon oppikken die in klassieke vragenlijsten verborgen bleven. Tot slot nam ik interviews af met zorgverleners in de

oncologie, waaronder oncologen, psychologen en verpleegkundigen. Ik wilde nagaan of zij dachten dat de experience sampling methode ook een plaats kan hebben in de praktijk. De zorgverleners zagen er inderdaad waarde in: de experience sampling methode zou hen kunnen helpen om sneller noden bij patiënten te herkennen en tijdige en persoonlijke zorg te bieden. Tegelijk wezen ze op een aantal bezorgdheden die eerst moeten worden aangepakt vooraleer de experience sampling methode echt in de dagelijkse praktijk kan worden toegepast.

Samengevat toont dit werk aan dat de experience sampling methode haalbaar en nuttig is voor mensen met gevorderde kanker. Het legt de basis voor toekomstig onderzoek naar wat de dagelijkse schommelingen precies veroorzaakt en hoe deze methode kan worden geïntegreerd in de routinezorg.

List of chapters

Chapters 2 to 8 of this dissertation are based on the following publications.

Chapter 2

Geeraerts, J., de Nooijer, K., Pivodic, L., De Ridder, M., & Van den Block, L. (2024). Intensive longitudinal methods among adults with breast or lung cancer: scoping review. *Journal of Medical Internet Research*, *26*, e50224. https://doi.org/10.2196/50224

Chapter 3

Geeraerts, J., Pivodic, L., Rosquin, L., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2024). Uncovering the daily experiences of people living with advanced cancer using an experience sampling method questionnaire: development, content validation, and optimization study. *JMIR Cancer*, *10*(1), e57510. https://doi.org/10.2196/57510

Chapter 4

Geeraerts, J., Pivodic, L., De Nooijer, K., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2024). Investigating experiences of people with advanced breast or lung cancer in their natural context: protocol for an experience sampling study. *BMJ open*, *14*(2), e075752. https://doi.org/10.1136/bmjopen-2023-075752

Chapter 5

Geeraerts, J., Pivodic, L., Nooijer, K. D., Rosquin, L., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2025). The potential of experience sampling methods in palliative care. *Palliative Medicine*, *39*(2), 307-317. https://doi.org/10.1177/02692163241306242

Chapter 6

Geeraerts, J., Pivodic, L., de Nooijer, K., Rosquin, L., Decoster, L. Fontaine, C., Joris, S., Crombez, G., Naert, E., De Ridder, M., Van den Block, L. Uncovering Fluctuations in Daily Symptoms and Well-being Among People with Advanced Cancer: An Experience Sampling Methods Study. (Accepted at *Palliative Medicine*, 2025)

Chapter 7

Geeraerts, J., de Nooijer, K., Pivodic, L., Crombez, G., Decoster, L. Fontaine, C., Joris, S., Naert, E., De Ridder, M., Van den Block, L. A Comparison of In-The-Moment and Retrospective Patient-Reported Outcome Measures in Advanced Cancer. (submitted at *Supportive Care in Cancer*, 2025)

Chapter 8

Geeraerts, J., de Nooijer, K., Pivodic, L., Decoster, L. Fontaine, C., Joris, S., Naert, E., Crombez, G., De Ridder, M., Van den Block, L. Oncology Healthcare Professionals' Perspectives on the Clinical Utility of Experience Sampling Methods. (submitted at *European Journal of Cancer Care*, 2025)

PART I

GENERAL INTRODUCTION

CHAPTER 1

General introduction

This section describes the general background, research aims, methods, and outline of the dissertation.

Background

Prevalence of advanced breast and lung cancer

Cancer is a group of diseases characterized by the uncontrollable growth of abnormal cells and can start in almost any organ or tissue of the body.[1] In Belgium, more than 70.000 people currently receive a cancer diagnosis every year.[2] In 2022, approximately 15% of diagnosed females were diagnosed with breast cancer, while 12% of both diagnosed males and females received a lung cancer diagnosis.[2] This makes breast and lung cancer two of the most prevalent cancer types in Belgium.[2] Cancer impacts mostly older adults, with a median age of 64 years at diagnosis for breast cancer and 70 years for lung cancer.[2,3] Although 1 in 4 deaths in Belgium in 2022 was attributed to cancer, advances in cancer treatment have contributed to declining mortality rates for many cancer types, including breast and lung cancer.[2,3] As a result, the global population of people living with cancer continues to rise.[2,3]

When cancer cells spread from the primary tumor through the blood or lymphatic system to form a new tumor in nearby tissues or lymph nodes (stage III), or distant organs or tissues (stage IV), the disease is referred to as locally advanced or metastatic cancer, respectively.[1] Depending on the site of the primary tumor, these stages are generally less likely to be cured and have considerably lower survival rates than those at earlier stages. For instance, stage IV breast cancer and stage III or IV lung cancer, which this dissertation refers to as advanced cancers, reflecting that treatment for these stages is typically non-curative. Survival rates illustrate the severity of these stages: in Belgium, 40% of people with stage IV breast cancer and only 7% to 30% of people with stage III or IV lung cancer are expected to survive for more than 5 years after diagnosis.[2] The risk of having advanced cancer at the time of a cancer diagnosis differs considerably based on where the primary tumor is located. In Belgium, 8% of women who received a breast cancer diagnosis were at the most advanced stage, while 62% of women with lung cancer (and 67% of men) had advanced stages of the disease.[2] Importantly, people at these advanced stages typically face a higher risk of experiencing symptoms and problems that negatively impact the quality of their lives.[4]

Multidimensional needs and well-being of people with advanced breast or lung cancer

Despite effective strategies to reduce side effects of treatments and early support for patients in the disease trajectory,[5] the quality of life and well-being of many people with advanced cancer, including those with advanced breast or lung cancer, is significantly impaired.[4,6–8] These impairments consist of a combination of symptoms, problems, and

concerns across multiple domains.[4,6–8] Key impacted domains include the physical, social, psychological, and spiritual-existential well-being domains.[4,6–8] The impairing symptoms and problems can arise as a direct consequence of the tumor growth, but also as side effects of diagnostic procedures or (a combination of) treatments such as surgery, radiotherapy, chemotherapy, and/or immunotherapy.[6,8]

Looking at physical symptoms, literature reviews in oncology show that 35 to 96% of people with advanced cancer experience pain in their disease trajectory, 32 to 90% experience fatigue, and 10 to 70% experience breathlessness.[6,9,10] Other commonly experienced physical symptoms include anorexia, insomnia, and constipation.[9] Hence, people with advanced cancer often experience limitations in physical functioning, which can limit them in conducting everyday activities or interactions and requires them to adopt strategies to continue activities they find meaningful.[11] Cancer can also lead to social problems, such as feelings of social isolation, and to the shifting of family roles and dynamics, thereby also impacting the people close to the person with breast or lung advanced cancer.[12,13] Furthermore, the life-threatening nature of advanced cancer and the heavy impact that the disease and its treatment have on the body increase the risk of psychological distress, cognitive problems, and both spiritual and existential distress. Specifically, psychological distress is visible in the high numbers of people with advanced cancer that experience symptoms of depression or anxiety,[6,14] but also the aggravation of feelings of anger.[15,16] Furthermore, 30% of people with cancer exhibit cognitive impairment prior to treatment, rising to 75% during treatment, and 35% will continue having cognitive difficulties for months after treatment.[17] Spiritual or existential distress can also come up, for instance due to experiencing one's approaching death.[6,16,18] Specifically, this distress can relate to hopelessness, futility, meaninglessness, disappointment, remorse, death anxiety, and disruption of personal identity.[6] Importantly, research in oncology increasingly recognizes that these problems across multiple well-being domains do not happen separately but are often intertwined.[19–23] To date, a large part of palliative and supportive care is focused on alleviating the symptoms and problems mentioned above. For instance, important organizations such as the American Society of Clinical Oncology advocate for timely palliative care in this population, targeting the physical, social, psychological, and spiritual-existential well-being domains.[24]

While many people with advanced cancer experience distress in their disease trajectory, it is important to note that positive experiences can also arise.[25] For instance, studies have reported the strengthening of connections with loved ones and the increased perception of value in social relations,[13,26] as well as resilience and post-traumatic growth among people with cancer and their caregivers.[27,28] Moreover, reflection and re-evaluation of life choices can lead to finding more meaning and satisfaction in life.[25,29] As such, effective cancer care

should not only focus on alleviating problems and concerns, it should also aim to leverage the positive experiences and traits of people with advanced cancer.[25]

Assessment of symptoms and well-being

The assessment of the symptoms and well-being of people with advanced cancer is of vital importance for providing optimal care for people with advanced cancer and to continue to improve this care through the provision of novel scientific insights. Assessments enable the detection of patients' needs,[30] the facilitation of communication between healthcare providers and the patient,[30] the comparison of care regiments or facilities, and the acquisition of fundamental scientific insights that can be used to develop new treatments or supportive regiments.[31]

Traditionally, researchers have relied on structured questionnaires or qualitative interviews to assess patients' experiences regarding their well-being and health, or regarding the care they receive. Interviews often provide a more open format that can be useful to gain deep insight into patients' needs and experiences. Structured questionnaires provide more standardized insights that can, for instance, allow the statistical comparison of clinical outcomes between patients in different treatment or intervention groups. These questionnaires can be collected directly from the patient, which is most commonly referred to as patient-reported outcome measures (PROMs), or indirectly through proxy reporting via, for instance, healthcare professionals or patients' family carers.[32] In cancer care, PROMs are increasingly used and promoted to aid in managing individual patients' care.[33,34] Benefits associated with the use of PROMs in clinical practice are better patient satisfaction,[35] perceptions of quality of care,[36] patient-provider communication,[35,37] shared decision making,[30] detection of unrecognized needs,[35] and symptom management.[38]

Most often, PROMs assess patients at single time points or over lengthy intervals and thus ask patients to remember and aggregate their experience(s) over a period of several days or weeks (e.g., "During the past 7 days, how tired were you?").[32] While this approach has proven to be valuable, it also holds certain limitations. Specifically, traditional PROMs do not capture patients' experiences as they unfold in real-time and they lack insight into patients' daily lives. This prevents the study of the interplay between patients' experiences and determining contextual factors in daily life, such as the activities they perform or the social company they keep. Importantly, retrospective questionnaires also come with risks of bias, such as recall biases. Examples include primacy and recency effects, saliency effects, and mood-congruent recall.[39,40] Given that many patients still experience debilitating symptoms and problems despite effective palliative and supportive cancer care,

exploring new approaches to study and address these problems could provide valuable insights for more effective, personalized support.

Experience sampling methods

Definition and general use

To provide novel insights into patients' symptoms and problems, experience sampling methods (ESM), also called ecological momentary assessments (EMA), may be suitable. The term ESM was first used in 1977 by Csikszentmihalyi, Larson, and Prescott as a research method to study people's daily lives and has thereafter been further developed and utilized in domains such as mental health and pain research.[41,42] The methods typically require people to complete multiple self-report questionnaires per day for several consecutive days or weeks, which allows for the study of time-varying experiences as they occur in daily life.[39] While older studies used paper questionnaires combined with pagers to administer ESM assessments, recent studies almost exclusively use smartphone-based assessments.[43]

The questionnaires of ESM often measure experiences such as symptoms, affects, behaviors or thoughts, and their context in the moment, e.g., "At this moment, I feel tired" and "What were you doing right before the beep?".[39] Participants then typically rate their momentary experiences using a response scale, such as a visual analogue scale ranging from 0 to 100 ("Not at all" to "Very much"), or for context questions select one or more response options from a multiple choice scale. Depending on factors such as the research question at hand or the expected burden that will be placed on participants, ESM has many options for configuring a research design.[44] For instance, researchers can determine the questionnaire content and phrasing, the number of assessments per day, the duration of the ESM period, and the timing of the assessments. Assessments may be scheduled at consistent, predetermined times (e.g., 12:00 PM) or be randomly distributed within fixed time intervals (e.g., between 10:30 AM and 12:00 PM), referred to as fixed and semi-random ESM designs, respectively. Fixed schedules are considered to impose less strain on participants, whereas semi-random approaches are thought to capture participants' day-to-day experiences in a more ecologically valid way.[45] The latter comes from the fact that assessments "sample" random moments out of the participants' life and the timing of the assessments cannot be anticipated. To date, studies that used ESM have mostly studied emotions, mental health, and physical health and health behaviors, and were mostly conducted in samples of healthy participants.[46] Overall, studies followed participants with ESM for a median of 7 days, using a median of 6 assessments per day.[46]

ESM could have several benefits compared to traditional retrospective PROMs or qualitative interviews. First, using repeated assessments, they can capture the fluctuations of patients' experiences in daily life.[44] Moreover, capturing fluctuations in experiences enables the study of associations between experiences and even contexts, which could provide insight into the mechanisms and triggers underlying symptoms and problems. Second, ESM improve ecological validity, as they study the individual in their natural environment (e.g., not solely in the hospital or in the psychological lab).[39] Third, as the items are phrased to pertain to the current moment or right before the "beep" or prompt, participants are not required to remember or recall their experiences over a long period of time. Therefore, ESM is thought to reduce memory recall biases that can be apparent when using traditional assessment methods.[39,40]

Use of experience sampling methods in oncology

Given the potential of ESM to uncover critical experiences of people with cancer in daily life,[47] studies in oncology have started increasingly using these methods.[48,49] A 2023 review identified 42 studies that used ESM in oncology,[48] while a more extensive review in 2024 (Chapter 2 of this dissertation) identified 13 studies performed in people with breast or lung cancer alone.[49] Only very few studies were conducted among people with advanced cancer. Furthermore, no studies used intensive assessment schedules (e.g., 10 assessments per day), with most of the studies prompting participants less than four times per day.[49] Notably, this amount of assessments is considerably lower than the median of 6 assessments per day that are reported in general research using ESM.[46] Positively, these lower-intensity type ESM studies appeared feasible and acceptable for use in people with cancer, with the limited amount of studies in advanced cancer suggesting the same.[48,49] However, although intensive assessment schedules with more frequent assessments per day may better capture experiences that are expected to rapidly fluctuate in daily life, their feasibility and potential burden on participants with advanced cancer remains unknown.

While ESM has traditionally been employed in research contexts, the methods are now also increasingly implemented in clinical practice, predominantly in mental health care.[39] In oncology, only a limited number of studies have looked into potential clinical applications of ESM.[49] Studies in advanced cancer have mainly tested the use of repeated in-the-moment assessments for symptom monitoring and management tools, allowing clinicians to quickly respond to high levels of real-time experienced symptoms, such as pain or fatigue, via clinician alarms.[50–53] This led to reductions in pain and fatigue, feeling more assured, and improved self-perceived symptom management.[50,52,53] ESM responses were also used to adapt the dose of anti-cancer treatment, allowing for acceptable levels of treatment toxicities.[54] This led to both patients and healthcare professionals feeling

reassured by the monitoring during out of hours.[54] In another study, ESM was used to create personalized charts that showed associations between fatigue, mood, activity, responding, and context for single individuals.[21] The feedback charts provided patients with insight into their cancer-related fatigue and provided psychotherapists with help on case conceptualizations.[21]

Research gaps to address regarding experience sampling methods in advanced cancer

Although ESM has the potential to provide new insights into the daily symptoms and well-being of people living with advanced cancer, several gaps need to be addressed before wider use of the methods in research and/or practice. First, it is unlikely that existing ESM questionnaires can be directly transferred to people with advanced cancer as these questionnaires have not been developed and validated specifically for this population. Yet, using validated questionnaires is of vital importance for the relevance and correct interpretation of study findings. Second, the use of ESM has been limited in people with advanced cancer, especially the use of high-intensity assessment schedules. Given that people with advanced care are often already burdened by the disease and its treatment, it is still uncertain if the repeated daily assessments of ESM are feasible and acceptable in this population. Third, it is unclear how responses to the repeated in-the-moment assessments of ESM relate to those captured with traditional retrospective questionnaires. This is knowledge is important, as it could provide insight into when the use of ESM is preferred over traditional questionnaires and vice versa. Fourth, as the use of ESM in mental health care is increasingly gaining popularity, it appears that ESM could be adapted to the context of oncology clinical practice. Yet, it is currently unclear what the views of oncology healthcare professionals are on the use of ESM in clinical practice.

Aims of this dissertation

The overarching aim of this dissertation is to uncover the potential of experience sampling methods (ESM) for understanding symptoms and well-being of people living with advanced breast or lung cancer.

To do so, this dissertation comprises three core aims, each divided into objectives as specified below.

Aim 1: To inform the adaptation of ESM for people with advanced breast or lung cancer and develop a questionnaire for measuring their in-the-moment symptoms and well-being of this population in daily life (i.e., experiences spanning the four well-being domains), and the variation of experiences within and between subjects.

Objective 1: To inform the adaptation of ESM for people with breast and lung cancer, by describing the extent to which intensive longitudinal methods with daily electronic assessments, such as ESM and daily diaries, have been used among patients with breast or lung cancer, along with the applied methodologies, associated outcomes, and factors influencing their implementation. (*Chapter 2*)

Objective 2: To develop, content-validate, and optimize the Experience Sampling Method for People Living With Advanced Cancer (ESM-AC) questionnaire. (*Chapter 3*)

Aim 2: To evaluate the use of ESM to assess symptoms and well-being of people with advanced breast or lung cancer in daily life.

Objective 3: To develop a protocol for a study to methodologically evaluate the use of ESM in people with advanced breast or lung cancer. (*Chapter 4*)

Objective 4: To assess the preliminary feasibility and acceptability of using the novel ESM-AC questionnaire in an intensive ESM study. (*Chapter 5*)

Objective 5: To evaluate the feasibility and acceptability of ESM for people with advanced breast or lung cancer, and its potential to uncover moment-to-moment fluctuations in symptoms and well-being. (*Chapter 6*)

Objective 6: To compare in-the-moment ESM responses with 7-day recall assessments of symptoms and well-being among people with advanced breast or lung cancer and to explore factors associated with discrepancies found between the methods. (*Chapter 7*)

Aim 3: To evaluate the clinical utility of ESM in oncology clinical practice.

Objective 7: To explore healthcare professionals' views on the clinical utility of ESM in oncology clinical practice. (*Chapter 8*)

Methods

To meet the research objectives of this dissertation, we employed several methods. We systematically conducted a scoping review of literature that reported on the use of intensive longitudinal methods in people with breast or lung cancer (**Chapter 2**). We conducted semi-structured interviews with patients and healthcare professionals to develop, content-validate, and optimize a smartphone-based ESM questionnaire (**Chapter 3**). Then, we drafted a research protocol to plan and describe all aspects of the methodological evaluation of the use of ESM in people with advanced cancer (**Chapter 4**). To test the preliminary feasibility and acceptability of ESM, we conducted a pilot study in a small sample of people with advanced breast or lung cancer and, based on its results, optimized the ESM design (**Chapter 5**). Afterwards, we used the optimized ESM design in an observational study in a larger group of people with advanced breast or lung cancer to evaluate the feasibility and acceptability of ESM, as well as its ability to capture fluctuations in symptoms and well-being (**Chapter 6**). We also used the responses of the observational ESM study to examine how ESM responses relate to those captured with traditional PROMs (**Chapter 7**). Finally, we conducted semi-structured interviews with oncology healthcare professionals to explore their views on the use of ESM in oncology clinical practice (**Chapter 8**). The methods for each study are briefly described in the following paragraphs, with more detailed descriptions in their corresponding chapters.

Research aim 1: Adaptation of ESM for advanced cancer

Scoping review of intensive longitudinal methods for people with breast or lung cancer

To meet research objective 1, we conducted a scoping review of studies reporting on the use of intensive longitudinal methods in adults with breast or lung cancer (Chapter 2). We systematically searched the electronic databases of PubMed, Embase, and PsycINFO for relevant articles. We screened titles and abstracts first, followed by full texts. We included articles that were performed in adults diagnosed with breast or lung cancer, used self-report or proxy responding with at least part of the sample reporting experiences through electronic devices, required conscious reporting of experiences (as opposed to passive data collection through wearables), assessed participants for longer than 24 hours, with at least 5 planned assessments over the ESM period and at least one assessment per day. Studies had to have full-text articles in English, Dutch, or French. We extracted data from the included articles, including (1) the characteristics of the populations with breast or lung cancer among whom intensive longitudinal methods with daily electronic assessments have been used; (2) the objectives, design, and methods used; (3) the results obtained

(including study findings and response-related results); and (4) the identified barriers and facilitators for implementing these methods in clinical and research practice.

Questionnaire development through interviews with patients and healthcare professionals

To meet research objective 2, we conducted an interview study, containing multiple rounds of interviews with people with advanced breast or lung cancer and oncology healthcare professionals (Chapter 3). We invited Dutch-speaking adults with stage IV breast or stage III to IV lung cancer from two hospitals in Brussels and Aalst, and a multidisciplinary mix of oncology healthcare professionals in the study. The goal of the ESM questionnaire that we aimed to develop was to comprehensively assess relevant daily experiences (i.e., symptoms and well-being) of people with advanced breast or lung cancer and the context in which these experiences occur.

Before the interviews, we created an initial list of items that could be relevant to measure multiple times per day, using established PROMs and an ESM item repository.[32,55] In the first round, we discussed all items individually with both patients and healthcare professionals to shorten the initial item list and determine its content validity. We focused on items' relative importance, relevance, appropriateness, and comprehensiveness, for which we followed the COSMIN guidelines for determining content validity and the EORTC guidelines for module development.[56,57] In the second round, we interviewed patients to finalize the content-validation of the questionnaire, mainly focusing on the comprehensibility of the items.[56] Finally, in the third round, we conducted interviews with patients to assess the usability of the digital ESM questionnaire in the m-Path application.[58] We used findings of the last round to optimize the digital questionnaire, making it ready for administration in an ESM protocol.

Analyses. We calculated descriptive statistics of all psychometric outcomes. Additionally, we used conventional content analysis on the interview transcriptions to develop content categories for participants' reasons for lack of item relevance, inappropriateness, problems with comprehensibility, themes of novel items to add, and difficulties or conveniences in the user experience or comprehension of the digital questionnaire.[59] We used all of the outcomes to continuously adapt the questionnaire.

Ethical considerations. All participants received an information letter and provided written informed consent. The study was approved by the central ethics committee of the university hospital of Brussels (BUNs: 1432021000533 and 1432023000043) and by the

local committee of the general hospital of Aalst, Belgium. Participating healthcare professionals received a €25 gift card.

Research aim 2: Methodological evaluation of ESM

Study protocol

To meet research objective 3, we planned and drafted a research protocol for the studies mentioned below (Chapter 4).

Pilot ESM study

To meet research objective 4, we conducted a pilot observational ESM study in adults with Stage IV breast or Stage III to IV lung cancer, recruited from two university hospitals in Brussels and Ghent (Chapter 5). Participants completed a baseline session, a 6-day ESM period in which they received 10 assessments per day, and a follow-up interview preferably up to 3 days after the ESM period.

At baseline, participants received a smartphone device with the ESM-AC questionnaire available in the installed m-Path application.[58] Participants also completed a baseline questionnaire on their socio-demographic information and smartphone familiarity and received training and an instructional page on how to use the smartphone and questionnaire. Over the next 6 days, participants then received up to 10 assessments per day at random times within equally spaced time blocks. At most three days after the last ESM assessment, the researcher collected the smartphone and administered a follow-up questionnaire on the participants' experiences with the method. The researcher noted participants' feedback and challenges throughout the study.

Analyses. We calculated descriptive statistics of sample characteristics, study metrics, and follow-up questionnaire responses and created time series graphs of the continuous ESM items to highlight the variability of participants' symptoms and well-being over time. We also conducted inductive content analysis on participants' feedback and challenges.[59]

Ethical considerations. All participants received an information letter and provided written informed consent. The study was approved by the ethics committees of the university hospital of Brussels and Ghent, Belgium (BUN: 1432023000043). Participants were instructed to call the researchers at any time if they had questions or difficulties regarding the study or the smartphone. Additionally, the researcher called patients after 1 day of ESM assessments to make sure there were no questions or technical problems. In case of signs of distress during researcher-participant contact, the researcher cited the participant's option to end the study without any negative consequences.

Observational ESM study

To meet research objectives 5 and 6, we conducted an observational ESM study with adults with Stage IV breast or Stage III to IV lung cancer (Chapters 6 and 7). The inclusion criteria and procedures were analogous to those reported under '3.2.2 Pilot ESM study', but we included a larger sample of patients. Additionally, participants completed a follow-up questionnaire that had the same items as the ESM-AC questionnaire, but phrased retrospectively (i.e., "During the past week, I felt …"). We described the outcomes and analyses of the two objectives separately below.

Analyses: Feasibility, acceptability, and ability to capture fluctuations. We evaluated feasibility through descriptive statistics and simple linear regression models of response data (e.g., enrollment, attrition, and questionnaire completion rates), and acceptability through descriptive statistics of follow-up questionnaire responses measuring burden, ease-of-use, instruction clarity, and measurement reactivity (Chapter 6). We analyzed fluctuations of symptoms and well-being over time using descriptive statistics such as within-person standard deviations, intra-class correlation coefficients, and floor and ceiling effects, and we plotted time series graphs.

Analyses: Relation between ESM and traditional PROM assessments. We compared 16 symptom and well-being items across multiple domains that were assessed with both in-the-moment ESM and a retrospectively follow-up questionnaire (Chapter 7). We compared the item scores using visualizations and correlations, and examined factors that were associated with discrepancies using linear regression models.

***Ethical considerations*.** Ethical considerations of the observational ESM study are identical to those reported under "3.2.2 Pilot ESM study".

Research aim 3: Evaluation of ESM's clinical utility in oncology

Interviews with healthcare professionals

To meet research objective 7, we performed semi-structured interviews with a multidisciplinary mix (in terms of their educational background and profession) of healthcare professionals from the University Hospital of Brussels (Chapter 8). We discussed with participants their previous experience with monitoring tools and computer technology, a visualization of patients' ESM responses from the observational ESM study, their perspectives on purpose and added value of ESM in clinical practice, factors that could

influence implementation of the methods in practice, and their preferences regarding the use of ESM in practice.

Analyses. We used qualitative content analysis to generate content categories describing the views of healthcare professionals on the clinical utility of ESM in oncology clinical practice.[59] This included the following steps: familiarization with the transcriptions, initial coding, category development to create a coding frame, creation of coding scheme, trial coding to refine the coding frame, final coding, and reporting and interpretation of the resulting coding frame.[59]

Ethical considerations. All participants received an information letter and provided written informed consent. The study was approved by the ethics committees of the university hospitals of Brussels and Ghent, Belgium (BUN: 1432023000043).

Dissertation outline

This dissertation consists of a general introduction (**PART I**, **Chapter 1**), main findings divided into three parts as per study aims (**PARTS II to IV**), containing **Chapters 2 to 8** as per research objectives, followed by a general discussion (**PART V**). Chapters 2 to 8 are based on manuscripts which have been published or submitted for publication as peer-reviewed articles in scientific journals. All chapters can be read as independent parts.

PART II of this dissertation focusses on the informing the adaptation of ESM for people with advanced breast or lung cancer and developing a questionnaire for measuring in-the-moment symptoms and well-being in daily life and the variation of these experiences within and between subjects (***Aim 1***). **Chapter 2** presents an overview of the extent to which intensive longitudinal methods with daily electronic assessments have been used among patients with breast or lung cancer, along with the methodologies used, associated outcomes, and influencing factors. **Chapter 3** showcases the development, content-validation, and optimization of the Experience Sampling Method for People Living With Advanced Cancer (ESM-AC) questionnaire.

PART III concerns the evaluation of ESM for use in people with advanced breast or lung cancer (***Aim 2***). **Chapter 4** describes the protocol for the study that forms the foundation of the chapters that follow. **Chapter 5** presents the assessment of the preliminary feasibility and acceptability of the novel ESM-AC questionnaire using an intensive ESM protocol in a pilot study. **Chapter 6** concerns the evaluation of the feasibility and acceptability of ESM for people with advanced breast or lung cancer, and its ability to uncover moment-to-moment fluctuations in symptoms and well-being. **Chapter 7** explores how in-the-moment and 7-day recall assessments of symptoms and well-being relate among people with advanced breast or lung cancer.

PART IV is devoted to the evaluation of the clinical utility of ESM in oncology clinical practice (***Aim 3***), with **Chapter 8** exploring the views of healthcare professionals on the use of ESM in oncology clinical practice.

PART V presents an overview of the dissertations' main findings, the strengths and limitations of the research methods used, a discussion of the main findings, as well as recommendations and implications for research, practice, and policy.

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PART II

ADAPTATION OF ESM FOR ADVANCED CANCER

CHAPTER 2

Intensive longitudinal methods among adults with breast or lung cancer: scoping review

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This chapter is based on: Geeraerts, J., de Nooijer, K., Pivodic, L., De Ridder, M., & Van den Block, L. . Intensive longitudinal methods among adults with breast or lung cancer: scoping review. *Journal of Medical Internet Research*, *26*, e50224. https://doi.org/10.2196/50224

Abstract

Background

Intensive longitudinal methods offer a powerful tool for capturing daily experiences of individuals. However, its feasibility, effectiveness, and optimal methodological approaches for studying or monitoring experiences of oncology patients remain uncertain.

Objective

This scoping review aims to describe to what extent intensive longitudinal methods with daily electronic assessments have been used among patients with breast or lung cancer and with which methodologies, associated outcomes, and influencing factors.

Methods

We searched the electronic databases (PubMed, Embase, and PsycINFO) up to January 2024 and included studies reporting on the use of these methods among adults with breast or lung cancer. Data were extracted on population characteristics, intensive monitoring methodologies used, study findings, and factors influencing the implementation of these methods in research and clinical practice.

Results

We identified 1311 articles and included 52 articles reporting on 41 studies. Study aims and intensive monitoring methodologies varied widely, but most studies focused on measuring physical and psychological symptom constructs, such as pain, anxiety, or depression. Compliance and attrition rates seemed acceptable for most studies, although complete methodological reporting was often lacking. Few studies specifically examined these methods among patients with advanced cancer. Factors influencing implementation were linked to both patient (e.g., confidence with intensive monitoring system) and methodology (e.g., option to use personal devices).

Conclusions

Intensive longitudinal methods with daily electronic assessments hold promise to provide unique insights into the daily lives of patients with cancer. Intensive longitudinal methods may be feasible among people with breast or lung cancer. Our findings encourage further research to determine optimal conditions for intensive monitoring, specifically in more advanced disease stages.

Introduction

Background

People diagnosed with cancer, among which breast and lung cancer are the most prevalent diagnoses globally,[1] often experience various problems and concerns that affect their quality of life and well-being across physical, psychological, social, and spiritual domains.[2–6] Understanding the fluctuations, interactions, and contextual variations of the multidimensional problems and concerns in patients' daily lives is crucial to gain a comprehensive view of these patients' quality of life and to optimize patient-centered care. Such insights could lead to, among others, improvements in drug schedules and personalized treatment decision-making[7] and the identification of novel care intervention targets by identifying contexts or states that aggravate or buffer against certain problems and concerns.[8]

An effective way to gather insights into the daily and within-day variability of patients' quality of life and well-being is the use of intensive longitudinal methods. Bolger and Laurenceau[9] defined intensive longitudinal methods as "an umbrella term to encompass data collection methods that employ enough repeated measurements to model a change process for each subject." The authors specify a minimum number of 5 sequential assessments, as it enables the estimation of linear models within each participant.[9] Examples of such methods are daily diaries and ecological momentary assessments (EMAs), also known as experience sampling methods (ESM). While predominantly developed in psychological research, these methods recently gained more attention in other fields and clinical practice, including oncology, due to advancements in handheld computer technologies that enable easier implementation than traditional pencil-and-paper approaches.[9–13] Despite easier implementation of these methods, researchers and clinicians in the field of oncology still lack a clear understanding of available options for intensive longitudinal monitoring, their opportunities, pitfalls, and feasibility in populations experiencing high symptom burden. This underscores the need for a structured overview of the use and capabilities of these methods.

Currently, no systematically conducted literature review exists on the use of intensive longitudinal methods in monitoring people with cancer. One systematic review[14] provided the most recent overview of the use of EMA in people with cancer across 42 studies (23 and 8 studies included people with breast and lung cancer, respectively) and found considerable heterogeneity in the methodologies used. However, due to its inclusion criteria focusing solely on EMAs, a large group of studies monitoring patients on a once-daily basis was left out.[14] Furthermore, the review did not report on the barriers and

facilitators that were encountered during the implementation of ESM, which is crucial information for optimal use in practice.[14]

Objective

We aimed to describe to what extent intensive longitudinal methods with daily electronic assessments have been used among patients with breast or lung cancer, along with the methodologies used, associated outcomes, and influencing factors. We limited the scope of this review to these patient groups with the most prevalent cancer diagnoses for feasibility reasons to provide a more nuanced picture for these methods among these groups and to inform our own ongoing ESM project among these patient groups.[15] More specifically, we described the characteristics of the populations with breast or lung cancer among whom intensive longitudinal methods with daily electronic assessments have been used; the objectives, design, and methods used; the results obtained (including study findings and response-related results); and (4) the identified barriers and facilitators for implementing these methods in clinical and research practice.

Methods

Overview

We conducted a scoping review using a systematic search strategy to gain insight into the extent, range, and nature of current evidence on the use of intensive longitudinal methods with daily electronic assessments in people with breast or lung cancer, rather than providing evidence for a specific research question as in systematic reviews.[16,17] This manuscript adheres to the PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews).[18]

Eligibility Criteria

We included articles that met the following criteria: articles that (1) performed in people diagnosed with breast or lung cancer through self-report or proxy responding; (2) included people aged ≥18 years; (3) used *active* intensive longitudinal methods, meaning the conscious reporting of experiences rather than passive data collection through wearables without conscious participant involvement;[12] (4) collected self-reports using electronic devices or allowed participants to choose between electronic and pen-and-paper self-reports, resulting in a partial sample that opted for electronic assessments; (5) applied a measurement period of >24 hours, with ≥5 planned assessments, including at least 1 assessment per day; and (6) included original full-text articles in English, Dutch, or French.

Articles were excluded if they met one or both of the following criteria: articles that (1) were conducted in people in complete cancer remission and (2) concerned reviews, meta-analyses, notes, letters to editors, conference abstracts, or study protocols.

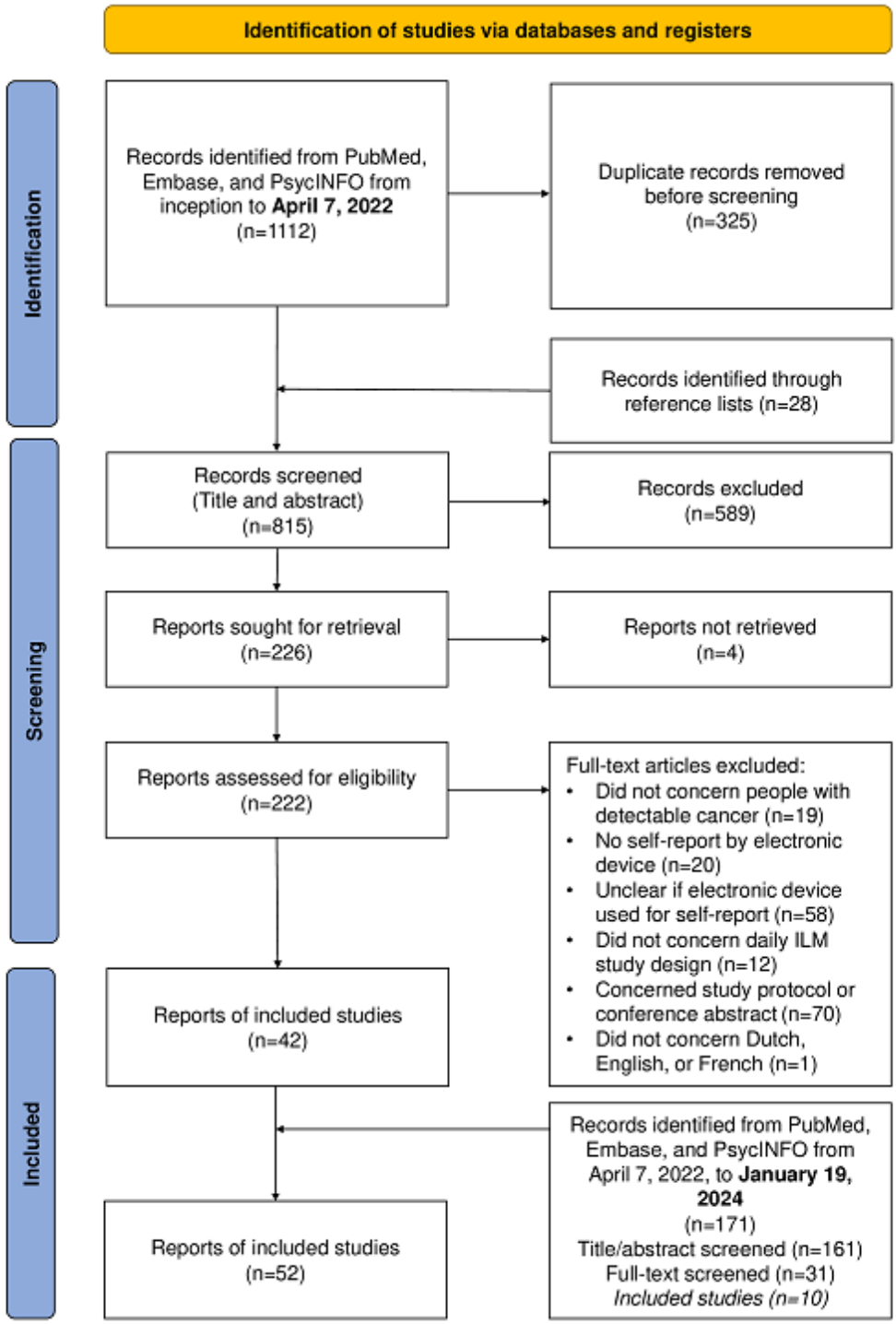
Search Strategy

The initial literature search was conducted on April 7, 2022, and updated on January 19, 2024, both without restrictions for its time coverage. We searched 3 databases: PubMed, Embase, and PsycINFO. We consulted a librarian of the Vrije Universiteit Brussel for the development of the search strategy. Keywords included terms related to the population (e.g., *cancer*) and methodology (e.g., *ecological momentary assessment* and *daily diary*). The search strategy was validated in PubMed and translated to other databases. The full search strategy is provided in Supplementary Material 1.

Study Selection

Figure 1 provides an overview of the selection procedure. Most duplicates were automatically detected and removed using EndNote (version 20; Clarivate).[19] Screening followed a 2-step process. First, 2 researchers (JG and KdN) independently screened titles and abstracts and labeled them as relevant, irrelevant, or potentially relevant for inclusion. Additional duplicates not detected by EndNote were removed during this step. Second, both reviewers screened the full texts of relevant and potentially relevant studies for final inclusion. JG and KdN resolved discrepancies in both steps through discussion and consensus and consulted a third and fourth reviewer (LP and LVdB), if necessary. JG screened articles found during the updated search. We used Rayyan (Qatar Computing Research Institute)[20] for reference management and manual removal of duplicates.

Figure 1. PRISMA-ScR (Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews) flow diagram. ILM: intensive longitudinal method.



Data Extraction and Synthesis

JG extracted data into a precreated MS Excel (version 16; Microsoft Corp) spreadsheet. To ensure consistency and accuracy of the initial search, KdN independently completed the data extraction form for a random 10% sample of included articles. JG and KdN discussed and resolved discrepancies. JG extracted updated search results. The data extraction form was revised throughout the review process. It included study characteristics (i.e., authors, year, country, and overarching study); sample characteristics (i.e., sample size, site of primary tumor, stage of disease, mean age, proportion of female participants, and comparison group characteristics); study aims and design; system characteristics (i.e., device, application, and operation system); daily questionnaire characteristics (i.e., number of items, constructs measured daily, existing measurement instruments, or sources used); sampling schedule characteristics (i.e., number of monitoring periods, duration of the monitoring periods, type of sampling scheme [i.e., fixed or random signal-contingent, event-contingent, or interval-contingent],[9] daily prompt frequency, and approximate time interval between prompts); supportive features for participants; response-related results (i.e., participation rate, attrition rate, proportion of completed prompts, and monetary incentives); and main study findings. We listed the barriers and facilitators for the implementation of the used method in research and clinical practice per study.

We have presented the study and sample characteristics, system and sampling schedule characteristics, and response-related results in the *Results* section, grouping articles reporting on the same study. We conducted content analysis on the extracted barriers and facilitators, inductively categorizing the content in themes and subthemes.

Results

Of the 1311 identified articles, we screened 253 (19.3%) full-text articles for eligibility. We included 52 articles, describing 41 unique studies (Figure 1).

Population Characteristics

All the 41 studies were conducted in high-income countries, except for 1 (2%) study in Türkiye[21] (all study and sample characteristics are listed in Supplementary Material 2).[21–72] We included 21 (51%) studies[22–44] reporting on samples of people with mixed primary tumor sites (including breast and lung cancer), 16 (39%) studies[21,45–66] on samples of people with breast cancer only, and 4 (10%) studies[67–72] on a sample of lung cancer only (Table 1). A total of 7 (17%) studies included patients' partners.[25,38,39,43,45-50,63] While 26 (63%) studies

were conducted in people at differing stages of disease, of which 11 (42%) included up to stage III[21,48–51,54–59,61,63,73] and 15 (58%) included up to stage IV,[23,25,26,31,32,34,36-39,41-44,53,64,69,70] 6 (15%) studies[24,30,33,35,45-47,52] specifically focused on people with stage IV cancer. Sample sizes ranged from 4[29] to 344[42] participants, with a mean of 54.3 (SD 56.4). The mean ages were 51 (SD 4.7) years for patients with breast cancer, 65 (SD 2.8) years for patients with lung cancer, and 58 (SD 5.7) years for patients with mixed primary tumor sites. None of the studies used proxy responding.

Table 1. Study and sample characteristics of the included studies (n=41).

Characteristics	Frequency of studies, n (%)	Reference, year
Primary tumor sites		
Breast	16 (39)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Cai et al[51], 2020 • Carson et al[52], 2021 • Çınar et al[21], 2021 • Dasch et al[53], 2010 • Kim et al[60], 2016 • Lim et al[64], 2022 • Min et al [61], 2014 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • Xu et al[63], 2019
Lung	4 (10)	• Dunsmore et al[72], 2023 • Maguire et al[71], 2015

Characteristics	Frequency of studies, n (%)	Reference, year
		• Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Steffen et al[69], 2018; Steffen et al[70], 2020
Mixed	21 (51)	• Aigner et al[22], 2016 • Besse et al[34], 2016 • Chumbler et al[23], 2007 • Coolbrandt et al[40], 2022 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Langer et al[25], 2018 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023 • Maguire et al[29], 2005 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Schuler et al[43], 2023 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023 • Weaver et al[33], 2014 • Yap et al[37], 2013
Included patients and partners	7 (17)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018; • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Langer et al[25], 2018; LeBaron et al[38], 2022 • LeBaron et al[39], 2023

Characteristics	Frequency of studies, n (%)	Reference, year
		• Schuler et al[43], 2023 • Xu et al[63], 2019
Disease stage		
I to II	1 (2)	• Shiyko et al[68], 2014; Shiyko et al[67], 2019
III to IV	9 (22)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Carson et al[52], 2021 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lim et al[64], 2022 • McCall et al[30], 2008 • Schuler et al[43], 2023 • Weaver et al[33], 2014
Mixed	20 (49)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Besse et al[34], 2016 • Cai et al[51], 2020 • Chumbler et al[23], 2007 • Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Langer et al[25], 2018 • McCann et al[31], 2009; Kearney et al[32], 2009 • Min et al[61], 2014 • Mooney et al[26], 2014 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58],

Characteristics	Frequency of studies, n (%)	Reference, year
		2022; Welch et al[65], 2023; Whitaker et al[63], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019 • Yap et al[37], 2013
Not fully mentioned	11 (27)	• Aigner et al[22], 2016 • Dunsmore et al[72], 2023 • Kearney et al[28], 2006 • Kim et al[60], 2016 • Lee et al[41], 2023 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Sztachańska et al[62], 2019 • van den Berg et al[27], 2022
Sample size		
4-20	9 (22)	• Besse et al[34], 2016 • Cai et al[51], 2020 • Hachizuka et al[35], 2010 • Kearney et al[28], 2006 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023
21-50	14 (34)	• Aigner et al[22], 2016 • Carson et al[52], 2021 • Chumbler et al[23], 2007 • Çınar et al[21], 2021 • Dunsmore et al[72], 2023

Characteristics	Frequency of studies, n (%)	Reference, year
		• Harper et al[24], 2012 • McCall et al[30], 2008 • Min et al[61], 2014 • Passardi et al[36], 2022 • Pinto et al[54], 2021 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Sztachańska et al[62], 2019 • van Roozendaal et al[44], 2023 • Weaver et al[33], 2014
51-100	13 (32)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Dasch et al[53], 2010 • Kim et al[60], 2016 • Lim et al[64], 2022 • McCann et al[31], 2009; Kearney et al[32], 2009 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2020; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Stone et al[59], 2016 • van den Berg et al[27], 2022 • Xu et al[63], 2019 • Yap et al[37], 2013
100-344	5 (12)	• Coolbrandt et al[40], 2022 • Langer et al[25], 2018 • Lee et al[41], 2023 • Mooney et al[26], 2014 • Nordhausen et al[42], 2022

Characteristics	Frequency of studies, n (%)	Reference, year
Mean age (years)		
40-50	10 (24)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Çınar et al[21], 2021 • Kim et al[60], 2016 • Langer et al[25], 2018 • Min et al[61], 2014 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Sztachańska et al[62], 2019 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019 • Yap et al[37], 2013
51-60	19 (46)	• Aigner et al[22], 2016 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Besse et al[34], 2016 • Cai et al[51], 2020 • Carson et al[52], 2021 • Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Harper et al[24], 2012 • Lee et al[41], 2023 • Lim et al[64], 2022 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • Stone et al[59], 2016 • van den Berg et al[27], 2022

Characteristics	Frequency of studies, n (%)	Reference, year
		• Weaver et al[33], 2014
61-70	9 (22)	• Chumbler et al[23], 2007 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Maguire et al[71], 2015 • McCall et al[30], 2008 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Steffen et al[69], 2018; Steffen et al[70], 2020
Not mentioned	3 (7)	• Kearney et al[28], 2006 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Maguire et al[29], 2005
Study design as reported by study authors		
Observational	30 (73)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Chumbler et al[23], 2007 • Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Kim et al[60], 2016 • Langer et al[25], 2018 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023

Characteristics	Frequency of studies, n (%)	Reference, year
		• Maguire et al[71], 2015 • McCall et al[30], 2008 • Min et al[61], 2014 • Nordhausen et al[42], 2022 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019 • Yap et al[37], 2013
Interventional	11 (27)	• Besse et al[34], 2016 • Cai et al[51], 2020 • Carson et al[52], 2021 • Çınar et al[21], 2021 • Lim et al[64], 2022 • Maguire et al[29], 2005 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Passardi et al[36], 2022 • Sztachańska et al[62], 2019 • Weaver et al[33], 2014

Characteristics	Frequency of studies, n (%)	Reference, year
Study objectives		
Feasibility, usability, or validity	19 (46)	• Besse et al[34], 2016 • Cai et al[51], 2020 • Chumbler et al[23], 2007 • Coolbrandt et al[40], 2022 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Kim et al[60], 2016 • LeBaron et al[38], 2022 • Lee et al[41], 2023 • Maguire et al[29], 2005 • McCall et al[30], 2008 • Min et al[61], 2014 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Schuler et al[43], 2023 • Solk et al[56], 2019 • Stone et al[59], 2016 • van den Berg et al[27], 2022 • Yap et al[37], 2013
Trajectory or relationship of variables	17 (41)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Langer et al[25], 2018 • LeBaron et al[39], 2023 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Shiyko et al[67], 2019

Characteristics	Frequency of studies, n (%)	Reference, year
		• Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • van Roozendaal et al[44], 2023 • Weaver et al[33], 2014 • Xu et al[63], 2019
Effectiveness of methods as intervention	4 (10)	• Çınar et al[21], 2021 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Maguire et al[71], 2015
Effectiveness of other interventions	3 (7)	• Carson et al[52], 2021 • Lim et al[64], 2022 • Sztachańska et al[62], 2019
Introduce statistical approach	1 (2)	• Shiyko et al[68], 2014

Study Design and Objectives

Of the 41 studies, 30 (73%)[22-25,27,28,30,37-50,53-61,63,65-67,69-72] used intensive methods in observational study designs, whereas 11 (27%)[21,26,29,31-34,36,51,52,62,64] used them in interventional studies. While 38% (20/52) of the articles[23,24,27-30,33,34,36-38,40-43,51,56,59-61] focused on the intensive method's feasibility, usability, or validity, other articles investigated the prevalence or trajectory of measured variables or relationships between those variables[22,25,39,44-50,53-55,57,58,63,65-67,69,70,72], the effectiveness of the intensive methods as an intervention[21,26,31,32,71], or the effectiveness of other interventions[52,62,64] or introduced a novel statistical approach[68].

Data Collection Methods

Daily Measured Constructs

Of the 41 studies, 30 (73%)[23-25,27-34,36,37,40-42,44-50,52-59,62,63,65-72] used items adapted from previous studies or scales (study details are listed in Supplementary Material 3)[21-72]. Some

of the most frequently recurring questionnaires were the Common Toxicity Criteria Adverse Events grading system,[29,31–33,37,41,74] EORTC Core Quality of Life Questionnaire (EORTC-QLQ-C30),[24,42,69,70,75] and the Positive and Negative Affect Schedule-Expanded scale.[48–50,53,69,70,76] Measured constructs covered physical, psychological, and social domains; behaviors and intentions; daily events; sleep quality; and general quality of life. The physical domain was the most assessed domain, with the most frequently measured constructs being pain[22,23,26,27,30,34,35,38-41,45-47,52,54,56,57,59,65-68,70] and fatigue[23,26-32,35,40,41,44,54-57,59,65,66,70]. Anxiety[22,26,35,41,51,54,56,57,59-61,65,66,72] and depression[26,35,51,56,57,59,61,65,66] were the most frequently measured constructs in the psychological domain, and social support[25,45,48,50,62] and communication[25,38,39,46,49,50,63] were the most frequently measured constructs in the social domain. Frequently measured behavioral constructs included medication use[22,36,38-40,47,61,64] and physical activity[38,39,56,57,65,66].

Sampling Schedule Characteristics

Of the 41 studies, 23 (56%)[21-24,26-28,30,37-41,43,48,50-53,59,61,62,69,70,72] required patients to fill in the questionnaire once per day, while 6 (15%) studies[25,29,31-34,67,68] required 2 completions daily, and 7 (17%) studies[35,44-47,54-58,63,65,66] required 3-6 completions daily (Table 2). Moreover, 5 (12%) studies[36,42,60,64,71] did not report the specific amount.

Table 2. Data collection methods used in the included studies (n=41).

Data collection methods	Frequency of studies, n (%)	Reference, year
Sampling schedule		
Once daily	23 (56)	• Aigner et al[22], 2016 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Cai et al[51], 2020 • Carson et al[52], 2021 • Chumbler et al[23], 2007 • Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Harper et al[24], 2012 • Kearney et al[28], 2006

Data collection methods	Frequency of studies, n (%)	Reference, year
		• LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023 • McCall et al[30], 2008 • Min et al[61], 2014 • Mooney et al[26], 2014 • Schuler et al[43], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • van den Berg et al[27], 2022 • Yap et al[37], 2013
Twice daily	6 (15)	• Besse et al[34], 2016 • Langer et al[25], 2018 • Maguire et al[29], 2005 • McCann et al[31], 2009; Kearney et al[32], 2009 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Weaver et al[33], 2014
3-6 times daily	7 (17)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Hachizuka et al[35], 2010 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019
Not mentioned	6 (15)	• Kim et al[60], 2016 • Lim et al[64], 2022 • Maguire et al[71], 2015

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Nordhausen et al[42], 2022 • Passardi et al[36], 2022
Sampling type[a]		
Fixed signal-contingent	15 (37)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Besse et al[34], 2016 • Cai et al[51], 2020 • Coolbrandt et al[40], 2022 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Langer et al[25], 2018 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Min et al[61], 2014 • Passardi et al[36], 2022 • Schuler et al[43], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Xu et al[63], 2019 • Yap et al[37], 2013
Random signal-contingent	7 (17)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Hachizuka et al[35], 2010 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2021; Welch et al[65], 2023; Whitaker et al[66], 2023 • van Roozendaal et al[44], 2023
Interval-contingent	6 (15)	• Çınar et al[21], 2021 • Dasch et al[53], 2010

Data collection methods	Frequency of studies, n (%)	Reference, year
		• McCall et al[30], 2008 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • Weaver et al[33], 2014
Event-contingent	6 (15)	• Hachizuka et al[35], 2010 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Maguire et al[29], 2005 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Schuler et al[43], 2023
Not clearly mentioned	15 (37)	• Aigner et al[22], 2016 • Carson et al[52], 2021 • Chumbler et al[23], 2007 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Kim et al[60], 2016 • Lee et al[41], 2023 • Lim et al[64], 2022 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • van den Berg et al[27], 2022
Data collection period length (days)		
5	1 (2)	• Yap et al[37], 2013
7	8 (20)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Cai et al[51], 2020 • Carson et al[52], 2021

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Kearney et al[28], 2006 • Pinto et al[54], 2021
8-13	3 (7)	• Otto et al[50], 2015 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Xu et al[63], 2019
14	7 (17)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Langer et al[25], 2018 • Maguire et al[29], 2005 • McCann et al[31], 2009; Kearney et al[32], 2009 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Sztachańska et al[62], 2019
>14	12 (29)	• Besse et al[34], 2016 • Çınar et al[21], 2021 • Lee et al[41], 2023 • Lim et al[64], 2022 • Maguire et al[71], 2015 • McCall et al[30], 2008 • Min et al[61], 2014 • Schuler et al[43], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • van den Berg et al[27], 2022 • Weaver et al[33], 2014
Variable per person	10 (24)	• Chumbler et al[23], 2007

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Coolbrandt et al[40], 2022 • Harper et al[24], 2012 • Kim et al[60], 2016 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Mooney et al[26], 2014 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Ratcliff et al[55], 2014 • van Roozendaal et al[44], 2023
Data collection devices for self-report assessments		
Smartphone	11 (27)	• Cai et al[51], 2020 • Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Langer et al[25], 2018 • Min et al[61], 2014 • Pinto et al[54], 2021 • Schuler et al[43], 2023 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019
Smartwatch	2 (5)	• LeBaron et al[38], 2022; LeBaron et al[39], 2023
Handheld computer	8 (20)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • McCall et al[30], 2008 • Ratcliff et al[55], 2014

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Shiyko et al[68], 2014; Shiyko et al[67], 2019
Mobile device with telephone or SMS functionality	9 (22)	• Besse et al[34], 2016 • Carson et al[52], 2021 • Lee et al[41], 2023 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Weaver et al[33], 2014 • Yap et al[37], 2013
Device with internet functionality	5 (12)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016
Specifically developed device	2 (5)	• Chumbler et al[23], 2007 • Nordhausen et al[42], 2022
Not mentioned	5 (12)	• Otto et al[50], 2015 • Kim et al[60], 2016 • Lim et al[64], 2022 • Passardi et al[36], 2022 • Sztachańska et al[62], 2019
Device ownership		
Patient-owned	19 (46)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Besse et al[34], 2016 • Cai et al[51], 2020 • Carson et al[52], 2021 • Çınar et al[21], 2021

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Lee et al[41], 2023 • Min et al[61], 2014 • Mooney et al[26], 2014 • Pinto et al[54], 2021 • Schuler et al[43], 2023 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2021; Welch et al[65], 2023; Whitaker et al[66], 2023 • Stone et al[59], 2016 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019 • Yap et al[37], 2013
Provided by researcher	12 (29)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Chumbler et al[23], 2007 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Nordhausen et al[42], 2022 • Ratcliff et al[55], 2014 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Weaver et al[33], 2014
Option to choose between patient-owned and research device	2 (5)	• Langer et al[25], 2018 • Steffen et al[69], 2019; Steffen et al[70], 2020
Not mentioned	10 (24)	• Otto et al[50], 2015 • Dunsmore et al[72], 2023

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Kim et al[60], 2016 • Lim et al[64], 2022 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Passardi et al[36], 2022 • Sztachańska et al[62], 2019
Data collection software[a]		
Smartphone apps	9 (22)	• Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Kim et al[60], 2016 • Langer et al[25], 2018 • Min et al[61], 2014 • Pinto et al[54], 2021 • Schuler et al[43], 2023 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023
Browser-based surveys (sent via chat, mail, or SMS)	6 (15)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Xu et al[63], 2019
SMS	3 (7)	• Besse et al[34], 2016 • Cai et al[51], 2020 • Yap et al[37], 2013

Data collection methods	Frequency of studies, n (%)	Reference, year
Interactive voice responding systems	4 (10)	• Besse et al[34], 2016 • Carson et al[52], 2021 • Lee et al[41], 2023 • Mooney et al[26], 2014
Other specifically developed software	12 (29)	• Aigner et al[22], 2016 • Chumbler et al[23], 2007 • Kearney et al[28], 2006 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCann et al[31], 2009; Kearney et al[32], 2009 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Ratcliff et al[55], 2014 • Stone et al[59], 2016 • Weaver et al[33], 2014
Not mentioned	8 (20)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Otto et al[50], 2015 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Lim et al[64], 2022 • McCall et al[30], 2008 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Sztachańska et al[62], 2019
Used conditional questionnaire items	7 (17)	• Badr et al[45], 2010; Badr et al[46], 2013 Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Coolbrandt et al[40], 2022 • Langer et al[25], 2018

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Mooney et al[26], 2014 • Shiyko et al[68], 2014; Shiyko et al[67], 2019
Used different questionnaire lengths depending on prompt timing	5 (12)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Langer et al[25], 2018 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023
The number of questionnaire items		
1-20	20 (49)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Besse et al[34], 2016 • Carson et al[52], 2021 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kim et al[60], 2016 • Langer et al[25], 2018 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Min et al[61], 2014 • Mooney et al[26], 2014 • Nordhausen et al[42], 2022 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Stone et al[59], 2016 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023 • Yap et al[37], 2013
21-40	6 (15)	• Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Lee et al[41], 2023 • Pinto et al[54], 2021 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Sztachańska et al[62], 2019
41-84	2 (5)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015
Not clearly mentioned	13 (32)	• Cai et al[51], 2020 • Chumbler et al[23], 2007 • Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Kearney et al[28], 2006 • Lim et al[64], 2022 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Passardi et al[36], 2022 • Weaver et al[33], 2014 • Xu et al[63], 2019
Supportive features		
Automated self-care advice	9 (22)	• Chumbler et al[23], 2007 • Coolbrandt et al[40], 2022 • Kearney et al[28], 2006 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCall et al[30], 2008

Data collection methods	Frequency of studies, n (%)	Reference, year
		• McCann et al[31], 2009; Kearney et al[32], 2009 • Weaver et al[33], 2014 • Yap et al[37], 2013
Clinician alerts	9 (22)	• Besse et al[34], 2016 • Coolbrandt et al[40], 2022 • Kearney et al[28], 2006 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Weaver et al[33], 2014 • Yap et al[37], 2013
Clinician could view summary of responses	5 (12)	• Coolbrandt et al[40], 2022 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Min et al[61], 2014 • Nordhausen et al[42], 2022
Informational modules	2 (5)	• Çınar et al[21], 2021 • Passardi et al[36], 2022
Module allowing communication with clinicians	1 (2)	• Çınar et al[21], 2021
Patients received response summaries	2 (5)	• McCall et al[30], 2008 • Xu et al[63], 2019
Relaxation reminders	1 (2)	• Çınar et al[21], 2021
None mentioned	23 (56)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018; • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Carson et al[52], 2021 • Dasch et al[53], 2010

Data collection methods	Frequency of studies, n (%)	Reference, year
		• Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Kim et al[60], 2016 • Langer et al[25], 2018 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023 • Lim et al[64], 2022 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • van den Berg et al[27], 2022 • van Roozendaal et al[44], 2023

[a]Multiple options possible per study.

Out of the 41 studies, 22 (54%) studies[25,34-40,43-51,54-58,61,63,65-70,72] applied signal-contingent sampling (i.e., prompting respondents to complete the questionnaire) and 6 (15%) studies[21,30,33,53,59,62] applied interval-contingent sampling (i.e., instructing respondents to complete the questionnaire at certain intervals), while 15 (37%) studies[22-24,26-29,31,32,36,41,52,60,64,71] did not specify the sampling method. Furthermore, 6 (15%) studies used event-contingent sampling on top of the other sampling methods; of these, 4 (67%) studies[29-32,38,39] instructed patients to complete the assessment when experiencing adverse events, 1 (17%) study[35] required the patients to assess when rescue medication was taken, and 1 (17%) study[43] prompted patients when a physiologically measured stress threshold was reached. Out of 22 signal-contingent sampling studies, 13 (59%)[25,34-37,43,48-

[51,61,63,69,70,72] prompted patients at fixed times, with times between prompts ranging from 3 to 24 hours. Moreover, 36% (8/22) of the studies[35,42,44-47,54-58,65-68] prompted patients at random times, of which 5 (62%)[35,44-47,55,67,68] randomly prompted within a fixed time block (e.g., between 9 AM and midnight). Minimum time intervals between randomly timed prompts ranged from 30 minutes to 3 hours[45-47,54-58].

Of the 41 studies, 7 (17%)[31-33,52,54-58,65,66,71] had multiple data collection periods for each patient. While the most common data collection period lengths were 7 days[28,35,48-54,71,72] and 14 days[22,25,29,31,32,45-47,62,67,68], ranging from 1 to 336 days,[42,60] 10 (24%) studies[23,24,26,36,38-40,42,44,55,60] mentioned differing study lengths for each patient (e.g., based on patients' next chemotherapy visit)[55].

System Characteristics

Data collection devices and software varied substantively in the included studies (n=41), with 11 (27%) studies[21,25,27,40,43,44,51,54,56-58,61,63,65,66] using smartphones, 1 (2%) study using smartwatches[38,39], and 8 (20%) studies[22,24,28,30,35,45-47,55,67,68] using handheld computers for self-report assessments. Other studies used basic telephone and SMS text messaging functionality[26,34,37,41,51,52], internet functionality[48-50,53,56-59,65,66,69,70,72], and used a specifically developed device[23,38,39]. A total of 19 (46%) studies[21,26,27,34,37,40,41,43,44,48-54,56-59,61,63] used patients' devices, whereas 12 (29%) studies[22-24,28,30,33,35,38,39,42,45-47,55,67,68] provided devices to patients.

Different types of software were used, including smartphone apps[21,25,27,36,40,43,44,54,60,61,63,64], browser-based surveys[48-50,53,56-59,63,65,66,69,70,72], SMS text messaging[34,37,51], interactive voice responding systems[26,34,41,52], and other specifically developed software applications[22,23,28,29,31-33,38,39,42,55,71].

Questionnaire Length

Some studies (7/41, 17%)[25,26,38-40,43,45-50,65-68] used conditional items that were presented when a certain response was given to previous items and different questionnaires depending on the timing of the prompt (e.g., the use of morning prompts to assess sleep quality[55,56]). Most studies (20/41, 49%)[21-25,27-29,31-35,37-40,42-47,51,52,55-61,63,65-68] had questionnaire lengths ranging between 1 and 20 items, with the longest being 84 items (including conditional items)[48-50]. Several studies (13/41, 32%)[21,23,28-33,36,40,51,63,64,71] did not provide complete information on the number of items.

Supportive Features

Of 41 studies, 17 (41%)[21,23,24,26,28-34,36,37,40,42,61,63,71] provided supportive features; 9 (22%) studies[23,28-33,37,40,71] offered automated self-care advice to patients based on their responses directly after response submission, for instance, offering advice for managing reported symptoms, with severe symptoms triggering advice to contact a health care professional.[73] Also, 9 (22%) studies[26,28,29,31-34,37,40,71] automatically contacted health care professionals based on symptom severity (i.e., clinician alerts). Some studies (2/41, 5%)[31,32,71] differentiated between different severities to indicate varying levels of need for immediate intervention (e.g., amber and red alerts). A total of 6 (15%) studies[28,29,31-33,37,71] combined automated self-care advice and clinician alerts. One study[26] alerted clinicians based on responses given on domains other than physical symptoms, namely psychological variables (i.e., depressive mood and anxiety) and distress caused by symptoms. Other supportive features included providing the opportunity to clinicians to view a summary or visualization of responses given by the patient[24,28,40,42,61] and providing patients with informational modules[21,36], modules allowing communication with clinicians[21,36], response summaries[30,63], and relaxation reminders[21].

Study-Reported Findings

Findings Concerning Methodological Evaluations

Intensive longitudinal methods that sampled once daily[23,26-28,30,37,40,42] or multiple times per day[33-35,38,43,56] were deemed feasible and acceptable for patients. These findings applied to various system characteristics, such as interactive voice response and SMS text messaging systems [26,34,37] and smartphone apps [27,40,43]. Compliance decreased over time in a 90-day study[61], with higher compliance among unemployed women. Patients believed in the method's ability to improve symptoms[29], symptom management[28,71], and communication with clinicians[71]. Moreover, patients had positive views on the usability of the methods[26,30,34,35,56,71] and felt reassured by using them[29,33].

Health care professionals had a positive view of the methods[71] and found them reassuring for patients, especially during out of hours[33], and clinically useful[26,30,37]. In addition, health care professionals thought that the methods could be helpful aids in timely interventions[29] and for assessing[28] and managing symptoms[28,29]. However, one study[24] reported that quality of life data was not used for making treatment decisions, and other studies[26,42,64] reported that clinicians rarely contacted the patients after receiving clinical alerts or monitored their responses. In one study[71], health care professionals mentioned that reduced complexity of the system was needed to promote its utility.

Some studies (5/41, 12%)[34,36,41,51,59] compared intensive longitudinal methods with other scales and found agreement between the methods, such as depression ratings and Patient Health Questionnaire-9.[60,77] One study[27] found a lack of agreement between the intensive methods and the Short Form Health Survey,[78] but this concordance improved with higher compliance rates.

Findings Concerning Prevalence and Covariability of Constructs

Several studies (16/41, 39%) examined the prevalence and covariability of constructs ranging across multiple topics. For instance, 7 studies[25,45,46,48-50,63] reported findings related to the social dynamics between patients and their partners. One study[45] found greater reports of relationship interference when patients experienced more pain and lower arousal mood. Moreover, partners were more likely to provide support when patients experienced more tiredness and less active mood resulting from pain.[45] Another study on this topic[48] found that partners' reports of support provision were positively associated with feelings of relationship intimacy reported by patients.

Overall, studies investigated various topics such as physical activity, affect, and physical symptoms. For instance, studies[54,65] showed associations between sedentary behavior, affective valence, and fatigue at different time points, analog to other studies[57,66] that found within-person associations between physical activity and same-day affect, fatigue, pain, and others.

Findings Concerning the Intensive Methods as an Intervention

Of the 41 studies, 7 (17%)[21,23,26,31,32,34,71] investigated the impact of intensive longitudinal methods as an intervention tool to improve symptoms, for instance, by providing automated self-care advice to patients or alerting clinicians when a certain symptom threshold was reached[71]. Patients in the intervention groups reported lower distress[21], lower fatigue, and higher levels of hand-foot syndrome[32] than those in the control groups. Patient-reported benefits included improved communication with health care professionals and symptom management and reassurance that symptoms were being monitored at home[31]. After the intervention, patients reported increased quality of life[21,23], lower anxiety and drowsiness, lower pain[34], and higher self-care efficacy[71] than at the baseline. One study using clinician alerts[26] found no improvements in symptom severity, explained by clinicians rarely contacting patients after alerts.

Response-Related Results

Of the 41 studies, 21 (51%)[22-26,33,34,37,40,43-50,52-54,56-58,63,65-67,69-71] reported participation rates ranging from 23.6% to 90.3% (mean 52.9, SD 3.4; Table 3; Supplementary Material 4)[21-72]. Overall, 17 (41%) studies[23,25,26,30,34,35,37-40,43,44,51,55,61,63,64,71] reported attrition rates, ranging from 0% to 56.9% (mean 19.7%, SD 17.7%). Furthermore, 19 (46%) studies[22,27,28,31-33,36,45-50,52-54,56-60,62,65-70,76] provided other attrition indicators, while 29 (71%) studies[22-27,33-35,40,42,43,45-47,50-67,69,70,72] reported compliance rates ranging from 44.2% to 98% (mean 74.9%, SD 16.4%).

Table 3. Response-related results of the included studies (n=41).

Results and characteristics	Frequency of studies, n (%)	Reference, year
Participation rate		
23%-25%	3 (7)	• Coolbrandt et al[73], 2021 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • van Roozendaal et al[44], 2023
26%-50%	8 (20)	• Aigner et al[22], 2016 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Carson et al[52], 2021 • Dasch et al[53], 2010 • Langer et al[25], 2018 • Maguire et al[71], 2015 • Xu et al[63], 2019 • Yap et al[37], 2013
51%-75%	4 (10)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018; • Pinto et al[54], 2021 • Schuler et al[43], 2023 • Weaver et al[33], 2014

Results and characteristics	Frequency of studies, n (%)	Reference, year
76%-90%	6 (15)	• Besse et al[34], 2016 • Chumbler et al[23], 2007 • Harper et al[24], 2012 • Mooney et al[26], 2014 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Steffen et al[69], 2018; Steffen et al[70], 2020
Not mentioned	19 (46)	• Otto et al[50], 2015 • Cai et al[51], 2020 • Çınar et al[21], 2021 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Kearney et al[28], 2006 • Kim et al[60], 2016 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023 • Lim et al[64], 2022 • Maguire et al[29], 2005 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Min et al[61], 2014 • Nordhausen et al[42], 2022 • Passardi et al[36], 2022 • Ratcliff et al[55], 2014 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • van den Berg et al[27], 2022

Results and characteristics	Frequency of studies, n (%)	Reference, year
Attrition rate		
0%-25%	12 (29)	• Cai et al[51], 2020 • Coolbrandt et al[40], 2022 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Langer et al[25], 2018 • Min et al[61], 2014 • Mooney et al[26], 2014 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • van Roozendaal et al[44], 2023 • Xu et al[63], 2019 • Yap et al[37], 2013
26%-57%	6 (15)	• Besse et al[34], 2016 • Chumbler et al[23], 2007 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lim et al[64], 2022 • Maguire et al[71], 2015 • McCall et al[30], 2008
Other indicators mentioned	18 (44)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018; • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Carson et al[52], 2021 • Dasch et al[53], 2010 • Kearney et al[28], 2006 • Kim et al[60], 2016 • Lee et al[41], 2023 • McCann et al[31], 2009; Kearney et al[32], 2009 • Passardi et al[36], 2022

Results and characteristics	Frequency of studies, n (%)	Reference, year
		• Pinto et al[54], 2021 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • van den Berg et al[27], 2022 • Weaver et al[33], 2014
None mentioned	5 (12)	• Otto et al[50], 2015 • Çınar et al[21], 2021 • Dunsmore et al[72], 2023 • Maguire et al[29], 2005 • Nordhausen et al[42], 2022
Compliance rate		
44%-60%	6 (15)	• Otto et al[50], 2015 • Kim et al[60], 2016 • Min et al[61], 2014 • Ratcliff et al[55], 2014 • Schuler et al[43], 2023 • van den Berg et al[27], 2022
61%-80%	10 (24)	• Aigner et al[22], 2016 • Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Besse et al[34], 2016 • Carson et al[52], 2021 • Coolbrandt et al[40], 2022 • Dunsmore et al[72], 2023 • Mooney et al[26], 2014 • Pinto et al[54], 2021

Results and characteristics	Frequency of studies, n (%)	Reference, year
		• Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Xu et al[63], 2019
81%-100%	13 (32)	• Cai et al[51], 2020 • Chumbler et al[23], 2007 • Dasch et al[53], 2010 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Langer et al[25], 2018 • Lim et al[64], 2022 • Nordhausen et al[42], 2022 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023 • Steffen et al[69], 2018; Steffen et al[70], 2020 • Stone et al[59], 2016 • Sztachańska et al[62], 2019 • Weaver et al[33], 2014
Other indicators mentioned	6 (15)	• Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Lee et al[41], 2023 • Passardi et al[36], 2022 • van Roozendaal et al[44], 2023 • Yap et al[37], 2013
Not mentioned	6 (15)	• Çınar et al[21], 2021 • Kearney et al[28], 2006 • Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009

Results and characteristics	Frequency of studies, n (%)	Reference, year
Monetary incentives		
Amount based on the number of completed assessments	6 (15)	• Badr et al[45], 2010; Badr et al[46], 2013; Stephenson et al[47], 2018 • Belcher et al[48], 2011; Pasipanodya et al[49], 2012 • Otto et al[50], 2015 • Langer et al[25], 2018 • Pinto et al[54], 2021 • Ratcliff et al[55], 2014 Steffen et al[69], 2018; Steffen et al[70], 2020
Fixed amount	5 (12)	• Cai et al[51], 2020 • Carson et al[52], 2021 • Stone et al[59], 2016 • LeBaron et al[38], 2022; LeBaron et al[39], 2023 • Solk et al[56], 2019; Phillips et al[57], 2020; Auster-Gussman et al[58], 2022; Welch et al[65], 2023; Whitaker et al[66], 2023
None provided	2 (5)	• Min et al[61], 2014 • van den Berg et al[27], 2022
Not specified	28 (68)	• Aigner et al[22], 2016 • Otto et al[50], 2015 • Besse et al[34], 2016 • Chumbler et al[23], 2007 • Çınar et al[21], 2021 • Coolbrandt et al[40], 2022 • Dasch et al[53], 2010 • Dunsmore et al[72], 2023 • Hachizuka et al[35], 2010 • Harper et al[24], 2012 • Kearney et al[28], 2006 • Kim et al[60], 2016 • Lee et al[41], 2023 • Lim et al[64], 2022

Results and characteristics	Frequency of studies, n (%)	Reference, year
		• Maguire et al[29], 2005 • Maguire et al[71], 2015 • McCall et al[30], 2008 • McCann et al[31], 2009; Kearney et al[32], 2009 • Mooney et al[26], 2014 • Nordhausen et al [42], 2022 • Passardi et al[36], 2022 • Schuler et al[43], 2023 • Shiyko et al[68], 2014; Shiyko et al[67], 2019 • Sztachańska et al[62], 2019 • van Roozendaal et al[44], 2023 • Weaver et al[33], 2014 • Xu et al[63], 2019 • Yap et al[37], 2013

Overall, 32% (13/41) of the studies provided monetary incentives, of which 8 (62%) studies[25,45-50,54,55,59,69,70] based attainable monetary amounts on the number of completed assessments, while 5 (38%)[38,39,51,52,56-58,65,66,72] provided patients with fixed amounts. Attainable monetary amounts ranged from US $40 to $200.

Barriers and Facilitators

Most studies reported the barriers and facilitators regarding the implementation of their methods in research or clinical practice (Table 4), either related to the person with cancer or the methods themselves. Some facilitating person-related factors included having confidence in using technology systems[31,56] and recognizing its clinical benefits[28,30,60]. Some person-related barriers were lack of smartphone ownership[40,61] and discomfort with technology[30,45-47,71]. However, inexperience with technology generally did not impact success with the study technologies[25,28,31,35]. However, smartphone users had higher compliance during an SMS protocol than basic phone users[37].

Table 4. Barriers and facilitators for the implementation of the method in practice and for research purposes, as stated by the papers' authors or extracted from the reported results.

Themes	Facilitators	Barriers
Factors related to the person with breast or lung cancer	• *Confidence* in their abilities to use technology systems[31,56] • Overall *preference for online diary* compared with paper diary[62] • Smartphone *users* had higher compliance than basic phone users[37] • *Recognize the clinical benefits* of using technology systems to report symptoms[28-30,42,60] and weigh these benefits against assessment burden[43] • *Willingness of patients*[30,42] • Patient *perceptions on the relevance* of the study to their needs[29] • *Sex, age, and diagnosis* did not impact compliance[42,43]; excluded participants appeared similar to the included participants[44] • *(Belief that) data are used* by clinicians[30,42,73]	• *Lack of interest or motivation* to participate can lead to small sample size[22] and lower compliance[42] • *Time constraints* affect participation rate and compliance[22,42,45,46] • *Symptoms and* side effects due to (advanced stage) illness and treatment may cause increased burden during study period, problems with pressing buttons, lower participation and compliance rates, and bias due to missing data[38,42,45-47,51,55,56,69] • Men were more likely to not use monitoring than women[26] • *Not owning a* smartphone prevents certain patients from using the monitoring system and thus participating in the study[61,73] • *Inexperience and discomfort about using the technology system* at start of the study period; particularly, *older adults* were less likely to participate[30,45-47,71] • *Caregiver status not easily verifiable through electronic health record*, disrupting eligibility screening[38] • Health care *professionals had doubts about the ability of patients* to complete electronic assessments[42] • Some patients *barely wearing or averse to wearing the study device*[38,43]

Themes	Facilitators	Barriers
		• *Dyad studies require informed consent from patient and caregiver*, leading to logistical challenges[38] • Difficulties *remembering experiences with using the system* after the study period[31]
Factors related to the method	• *Use of single items for constructs* to shorten questionnaire[39,48,58,69] reduces burden, improves adherence[39], and gives room for measurement of multiple constructs, possibly reducing reactivity to a single construct[69] • *Tailoring of sampling schedule to population of interest*, for example, limiting the frequency of assessments, to not overburden[67] or providing a broad enough window to respond in[53], possibly prompting the participant a second time if unanswered[55] • *Reminders or prompts*, including the option to tailor reminder schedules and contact by the researcher, might improve adherence[21,31,36,54,57,58,61] • Ability to use patients' *personal smartphones*[34,57], making the need for study visits to receive a specialized electronic study device obsolete[27,34,56] and providing a non-burdensome means to study individuals in their natural environment[27,34] • *Possibility to combine EMA[a] prompting with passive monitoring*	• *Single item constructs bring psychometric limitations*[39] • *Empty battery or low battery life*, possibly leading to device memory loss and missing data[38,45,46,51] • *Turned off phones or patients not wearing smartwatches* leading to missing data[38,51] • *Transmission or pairing errors*[33,38,42,51] can lead to frustrations[38] • Bugs in code *to monitor smartwatches*[38] • *Incompatibility issues* possible between smartphones' display specifications and the used app[61] • *Synchronization problems* related to automatic Android updates leading to inconsistent timing of EMA prompts[38] • *Poor reception* at home, for example, in rural areas[31,33], could cause necessity to switch SIM providers[33] • *Monitoring requires time and manpower* in a context with high clinician time constraints[37,42,71], possibly leading to fewer calls after clinician alerts[26], or lack of using monitoring results by clinical staff and trial investigators[42,64] • *Dependency of the implementation on* health care *professionals*,

Themes	Facilitators	Barriers
	through high-grade commercially available devices[43,57] • Using *electronic devices over paper-and-pencil* alternatives does not impact attrition[32] • *Portability* of mobile phones enables daily assessments[60], while smartwatches can enhance acceptability[38] • *Facial emotions scale* demands less cognitive effort, is less of a burden, and makes responding more enjoyable[60] • *"Unsure" response option* can improve data quality when patients are confused with a question[38] • *Simple questionnaire and system design* for an easier patient experience[29,31,42] • Option to report *additional information* after structured questionnaire for a better patient experience (e.g., additional symptoms and having preexisting conditions)[31] • *More time explaining how to respond* correctly to SMS response system can improve the quality of responding when the response format is expected to be difficult[37] • *Standardized protocol checklist* for researchers to streamline deployment installation[38] • *Providing participants with handouts* before the study period,	who are difficult to motivate to break the status quo[42] • *Vast amount of data* can be burdensome to clinicians[60] • *False-positive clinician alerts* due to errors in responding and transmission problems[33,37] • *Self-care information* not always read by patients[71] • Compliance to *time-blocked random signals* may be affected by participants waking up late or going to bed early[46] • *Developing EMA schemes can be challenging* when taking participant burden into account[39] • *Content irrelevant to patient* could cause dissatisfaction[37]; clinical monitoring measures should be tailored to their needs[42] • *24-hour recall may not be appropriate* to measure all symptoms[41] • *Unclear instructions* on when to complete event-contingent assessment can cause confusion among participants[38] • *Technical changes are complex and require time* to test and implement, but are often underestimated by clinical team[38] • In comparative trials*, electronic diary might bias patients* toward better self-management due to increased awareness and daily requirement to enter data[64]

Themes	Facilitators	Barriers
	including frequently asked questions and contact information in case of difficulties in using system[25] • *Easy and fast access to PROMs[b] and gathered data*, for example, by the integration of monitoring system into the electronic patient, likely leads more uptake in clinical settings[30,42,73] and makes IT support crucial[42] • *Cloud services system* improves the ability to securely offload and store data in real time[38] • *Reducing time delays between consent and deployment* can mitigate attrition and accommodate the dynamic clinical status of patients[38] • *Iterative deployments* can improve setting up and removing the system[38] • *Personal support by research assistant* is appreciated by patients[42] and might improve adherence[44]	• *Interruption of monitoring assessment* (e.g., due to diagnostics or therapy)[42] • *Rapid clinical staff turnover*[42]
Other factors	—[c]	• COVID-19 *pandemic*[38,42]

Note. We highlighted the influencing factors in italics.

[a]EMA: ecological momentary assessment.

[b]PROM: patient-reported outcome measure.

[c]Not applicable.

Some facilitating method-related factors included the ability to tailor sampling schedules to the population of interest[53,55,67] and the option to use reminders[21,31,36,54,57,58,61]. Some barriers included technical issues such as empty batteries leading to memory loss and missing data[38,45,46,51] and false-positive clinician alerts due to faulty responding and

transmission problems[33,37]. All these factors were associated with improvements in participation and compliance rates, user-experience, patient burden, quality of responses, time requirements for researchers, and adoption in clinical settings[21,22,25-34,36-38,40,42-48,51,55-58,60,61,67,69,71].

Discussion

Principal Findings

Intensive longitudinal methods with daily electronic assessments have been used among people with breast or lung cancer at different disease stages. The methods involved 1-6 assessments per day to study a wide range of experiences in daily life, primarily physical and psychological symptoms. Some studies integrated supportive features within the longitudinal assessments. For most studies, compliance and attrition rates were acceptable, although many studies lacked complete methodological reporting. Few studies focused on patients in the advanced stage of disease. We identified the barriers and facilitators for using these methods, related to both the person with cancer and the method itself.

Our review highlights the promise of intensive longitudinal methods to provide unique insights into the daily lives of people living with cancer. Importantly, these methods generally seem feasible and acceptable among patients with breast or lung cancer, supported by positive patient and health care professional experiences, along with compliance and attrition rates indicating acceptable amounts of missing data. These findings were true for different methodological approaches, such as studies that assessed patients once or multiple times daily. Moreover, these methods demonstrate flexibility as they were used to address an array of objectives, such as exploring within-person symptom associations[55] or communication patterns in dyads.[63]

Before widespread implementation of these intensive methods in oncology research and practice, several of our findings encourage further investigation into its feasibility and optimal study conditions. First of all, it is striking that response- and methodology-related reporting was often incomplete or reported in different ways (e.g., compliance rates and amount of questionnaire items). Standardized reports of this information are critical to inform optimal methodological choices in future studies or clinical procedures, as poor choices can lead to additional patient burden and missing data. Due to the unstandardized reporting by many included studies, comparisons in response-related results between studies with different methodological features were not possible in this review. Yet, such comparisons are particularly important when using intensive sampling methods in

populations who are already susceptible to increased disease-related burden. In addition, several identified factors need further exploration to enhance the implementation of intensive longitudinal methods with daily electronic assessments in research and practice, for example, participants' feelings of inexperience and discomfort with technology leading to a lower likelihood to participate in the study[30,45-47,71]. Finally, low participation rates of the included studies indicate participant recruitment to be difficult, and sample sizes were often small. This is a major barrier for research, as it could lead to sampling bias, for instance, through self-selected sampling of people more confident or experienced in using electronic systems. Subsequently, this could limit the validity of study findings.

Our review identified understudied areas that prevent gaining a complete understanding of people with breast or lung cancer and their daily experiences. First, several populations of people with breast or lung cancer are currently underrepresented in intensive longitudinal method studies, which significantly limits the generalizability of findings for these populations, including findings on the feasibility of these methods. For instance, of the 41 studies, only 4 (10%) were conducted in people with lung cancer specifically, 6 (15%) studies were conducted in people with stage IV cancer specifically, 1 (2%) study was conducted in a low-income country, and only 1 (2%) study included 1 male participant with breast cancer. Second, although the study objectives varied widely, studies predominantly focused on the aspects of physical health, such as pain, or had rather clinical views on psychological constructs by focusing on depression and anxiety. Only one included study[62] covered experiences from spiritual or existential quality of life domains, which is remarkable because these experiences generally have increasing value at the end of life[5,6]. Furthermore, although ESMs offer the potential for linking patient experiences with concurrent contexts (e.g., where the patient is and what they are doing)[12], these contextual aspects remain understudied among people with breast or lung cancer. A broader focus encompassing different domains and contexts is needed to gain a more comprehensive understanding of patients' quality of life and well-being, ultimately enabling the improvement of patient-centered care.

Implications for Practice and Research

On the basis of our findings, we provide several recommendations for practice and research. First, applying existing reporting guidelines for EMAs, such as those synthesized by Liao et al,[79] can improve transparency and consistency in reporting for intensive longitudinal studies in oncology. Their checklist serves as a starting point to fulfill recommended reporting criteria, such as reporting the use of prompts and complete questionnaire information.[80] This will allow future researchers to accurately explore the effects of study features on response-related results.

Second, addressing implementation factors highlighted in this review can be achieved through simple solutions, such as providing clear instructions, training on the use of the methods, and emphasizing the importance of the study to increase patient motivation and confidence[25,28-31,37,56,60]. Moreover, extensive pretesting such as conducting a pilot study is essential to uncover any technical issues that may arise.

Third, it is essential to determine optimal conditions for using intensive longitudinal methods with daily electronic assessments in people with cancer, such as ideal sampling schemes for the feasible measurement of specific constructs.[81,82] Studies should focus on populations at an increased risk for symptom burden, such as those with advanced stage cancer.[83,84] Furthermore, the use of supportive features such as automated feedback and clinician alerts needs more investigation to explore how it is optimally implemented in routine clinical practice for the best possible outcomes. Moreover, it is recommended to develop measures to examine the quality of responses provided by patients,[85] as these could be influenced by cancer and its treatment (e.g., through cognitive impairment).

Fourth, future studies among patients with breast and lung cancers could broaden their focus to encompass more nonclinical psychological or spiritual-existential topics and contextual factors. This approach could yield novel insights into the interplay between physical functioning and other aspects of well-being and how they vary in different contexts[8]. Researchers could look to other populations of people living with or beyond cancer to further inform on the possibilities of these methods. For example, studies involving survivors of cancer could have a less clinical focus due to living past the treatment stage. Future literature reviews of the use of daily methods among such populations would be greatly beneficial.

Finally, studies should further explore how multiple daily measurements compare with the same constructs as measured by the more commonly used patient-reported outcome measures in oncology, in which patients are expected to aggregate experiences over ≥1 weeks.[86,87] Such research could examine the ecological validity of these commonly used patient-reported outcome measures[59] and provide valuable insights for oncology research and practice regarding which experiences are more accurately measured on a more frequent basis.

Strengths and Limitations

This scoping review followed a broad systematic search strategy in multiple databases, incorporating studies that used self-report methods to assess patients daily or multiple times a day. Consequently, it offers a comprehensive overview of the methods used to

gain insight into the daily experiences of people with breast and lung cancers at various stages across different countries.

Nevertheless, this review has limitations. First, it is plausible that we missed studies that used different terms for their daily electronic self-report questionnaire than those used in our search string. However, the broadness of our search string minimized this risk, and we detected articles that reported on methods that could be classified as ESMs but were not identified by the previous review in 2019[12]. Second, only 10% of data extraction was checked by a second reviewer, and none were compared during the updated search, introducing a slight possibility of inaccuracies. We consider this a minor risk, as we found no disagreements in the 10% data that we had checked.

Conclusions

Intensive longitudinal methods using daily electronic assessments hold promise and can be feasible to provide unique insights into the daily lives of patients with breast or lung cancer. However, our findings encourage further research on the feasibility of determining optimal conditions for intensive monitoring, specifically in more advanced disease stages, and better adherence to standardized reporting guidelines. Moreover, considering a more multidimensional approach to the topics studied, especially beyond physical and psychopathological symptoms, will enhance the value of these methods, ultimately aiding in the improvement of patient-centered care in oncology.

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Authors' Contributions

All authors contributed to the conception and design of the study. JG and KdN acquired and interpreted the data. JG drafted the manuscript. All authors reviewed the final draft and provided the final approval.

Conflicts of Interest

None declared.

Supplementary Materials

Supplementary Material 1: Search terms.
Supplementary Material 2: Study and sample characteristics.
Supplementary Material 3: Content and design characteristics.
Supplementary Material 4: Response-related characteristics.

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CHAPTER 3

Uncovering the daily experiences of people living with advanced cancer using an experience sampling method questionnaire: development, content validation, and optimization study

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Abstract

Background

The experience sampling method (ESM), a self-report method that typically uses multiple assessments per day, can provide detailed knowledge of the daily experiences of people with cancer, potentially informing oncological care. The use of the ESM among people with advanced cancer is limited, and no validated ESM questionnaires have been developed specifically for oncology.

Objective

This study aims to develop, content validate, and optimize the digital Experience Sampling Method for People Living With Advanced Cancer (ESM-AC) questionnaire, covering multidimensional domains and contextual factors.

Methods

A 3-round mixed methods study was designed in accordance with the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) and the European Organization for Research and Treatment of Cancer guidelines. The study included semistructured interviews with 43 people with stage IV breast cancer or stage III to IV lung cancer and 8 health care professionals. Round 1 assessed the appropriateness, relative importance, relevance, and comprehensiveness of an initial set of ESM items that were developed based on the existing questionnaires. Round 2 tested the comprehensibility of ESM items. Round 3 tested the usability of the digital ESM-AC questionnaire using the m-Path app. Analyses included descriptive statistics and qualitative content analysis.

Results

Following the first round, we developed an initial core set of 68 items (to be used with all patients) and a supplementary set (optional; patients select items), both covering physical, psychological, social, spiritual-existential, and global well-being domains and concurrent contexts in which experiences occur. We categorized items to be assessed multiple times per day as momentary items (e.g., "At this moment, I feel tired"), once a day in the morning as morning items (e.g., "Last night, I slept well"), or once a day in the evening as evening items (e.g., "Today, I felt hopeful"). We used participants' evaluations to optimize the questionnaire items, the digital app, and its onboarding manual. This resulted in the ESM-AC questionnaire, which comprised a digital core questionnaire containing 31 momentary items, 2 morning items, and 7 evening items and a supplementary set

containing 39 items. Participants largely rated the digital questionnaire as "easy to use," with an average score of 4.5 (SD 0.5) on a scale from 1 ("completely disagree") to 5 ("completely agree").

Conclusions

We developed the ESM-AC questionnaire, a content-validated digital questionnaire for people with advanced breast or lung cancer. It showed good usability when administered on smartphone devices. Future research should evaluate the potential of this ESM tool to uncover daily experiences of people with advanced breast or lung cancer, explore its clinical utility, and extend its validation to other populations with advanced diseases.

Introduction

Background

Quality of life assessment among people with cancer often relies on retrospective patient-reported outcome measures (PROMs), which typically require patients to aggregate their experience over several days or weeks into 1 score (e.g., "During the past week, were you tired?").[1–3] This precludes temporally fine-grained knowledge on how cancer-related experiences such as physical or psychological symptoms and concerns change within and across days and the mechanisms underlying these changes. Moreover, studies found that retrospective PROMs often over- or underestimate in-the-moment somatic and psychological experiences across various populations, indicating a need for more fine-grained measures.[4,5] From a research and clinical perspective, this detailed knowledge on in-the-moment experiences is critical for improving patient symptom management and psychosocial support, such as by identifying novel intervention targets.

To bridge this gap, the experience sampling method (ESM),[6] also called ecological momentary assessments,[7] may be suitable. The ESM or ecologic momentary assessments involve repeatedly gathering self-reported data from participants in the context of their daily lives, often multiple times per day for several consecutive days through mobile devices such as smartphones.[7–9] Contrary to traditional PROMs, the ESM mitigates retrospective biases and improves ecological validity of findings by asking questions about momentary experiences in their natural environment (e.g., "At this moment, I feel...").[7] Moreover, the ESM provides the opportunity to study affect over time (i.e., experiences of feelings or emotions) as an important indicator of emotional functioning and psychological well-being[9–11] and to investigate patients' experiences together with concurrent contexts, such as the social environment.[12] Including contextual items can facilitate the identification of situations that alleviate or exacerbate certain experiences, thereby informing future psychosocial interventions.

Despite the ESM's potential to provide novel insights into the daily experiences of people with cancer, its use in oncology research remains limited, especially among people with advanced (i.e., metastatic) cancer.[9,12,13] Nevertheless, compared to people in the earlier stages of cancer, people with advanced cancer have a higher likelihood of experiencing symptoms and concerns that negatively impact their quality of life.[14,15] A possible explanation for the limited use of these methods among people with advanced cancer is that researchers may avoid them to prevent placing additional burden on patients through repeated assessments. However, to develop and improve interventions to alleviate these high levels of symptoms and distress, gaining a more detailed understanding of the well-

being of people with advanced cancer in the context of their daily life (i.e., its fluctuations, mechanisms, determinants, and consequences) is imperative; for this purpose, the use of the ESM is recommended.[16,17] The limited number of ESM studies among people with advanced cancer have investigated a range of symptoms, concerns, and measures of well-being across quality of life domains and provided evidence for the dynamic nature and associations thereof.[18–30] For example, Badr et al [21] found that greater pain in the morning was associated with feeling less aroused mood (e.g., more tiredness and less peppy) during the rest of the day for women with metastatic breast cancer, with pain and low arousal mood being associated with romantic relationship interference.

There is currently no validated ESM questionnaire designed specifically for people with advanced cancer.[9,13] Validity, especially content validity, is a crucial indicator of whether the content of an instrument is an adequate reflection of the construct being measured.[31,32] However, it is often overlooked in ESM research as a whole, leading to recent calls for more content validation of ESM questionnaires.[9,13,32,33]

By reporting the development, content validation, and optimization of an ESM questionnaire, this study is the first step of a larger project in which we aim to test the feasibility of the ESM and use it to obtain novel insights into the daily experiences of people with advanced cancer. Because symptoms can vary across different advanced cancer diagnoses and our aim was to develop a questionnaire that is highly relevant to the specific experiences of intended users, our project's scope is narrowed to people living with advanced breast or lung cancer. We selected these diagnoses as they are among the most prevalent cancer diagnoses with high mortality rates [34–36] and are associated with considerable risk for experiencing serious symptom burden.[37–41]

Objectives

In this study, we aimed to develop, validate, and optimize the Experience Sampling Method for People Living With Advanced Cancer (ESM-AC) questionnaire. The digital ESM questionnaire aims to comprehensively assess relevant daily experiences (i.e., symptoms, concerns, and well-being) of people with advanced breast or lung cancer and the context in which these experiences occur; it collects these data multiple times per day for several consecutive days.

Methods

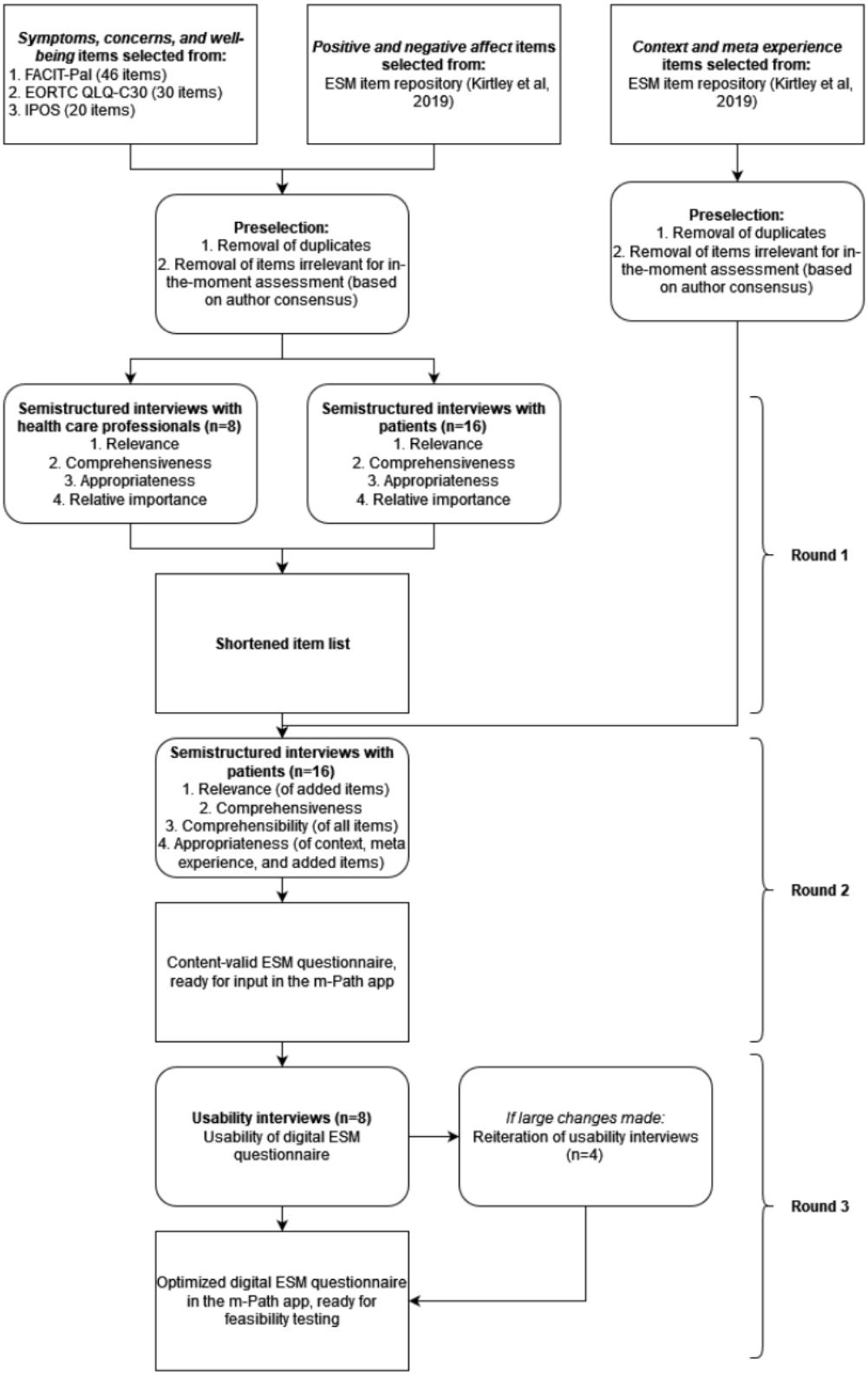
Study Design

We conducted a 3-round interview study with patients and health care professionals using a mixed methods research design (summarized in Figure 1). To develop and validate the ESM questionnaire in the first 2 interview rounds, we based our design on the guidelines of PROMs [31,42] because no specific guidelines for ESM questionnaires were available.[32] Specifically, the Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) methodology [31] guided the assessment of the content validity of our initial set of items in the first 2 rounds (i.e., covering relevance, comprehensibility, and comprehensiveness; refer to Textbox 1 for an overview of key psychometric concepts used in this study). In the first round, the item set was shortened and categorized into a core and supplementary item set based on content validity, appropriateness, and relative importance, following the European Organization for Research and Treatment of Cancer (EORTC) guidelines for module development.[42–44] The second round focused on the comprehensibility of all items and on the relevance and appropriateness of the items added after round 1. In the third round, we optimized the digital (core) ESM questionnaire by assessing barriers related to its usability for patients using the dedicated ESM smartphone app (i.e., m-Path; KU Leuven).[45]

Textbox 1. Key concepts with their respective definitions.

- Content validity: the extent to which the content of an instrument is an adequate reflection of the construct to be measured. This includes relevance, comprehensiveness, and comprehensibility.[31]
- Relevance: the extent to which a questionnaire item is relevant for the construct of interest within a specific population and context of use.[31]
- Comprehensiveness: the extent to which all key aspects of the construct are included in the questionnaire.[31]
- Comprehensibility: the extent to which a questionnaire item is understood by patients as intended.[31]
- Appropriateness: the extent to which a questionnaire item is perceived as appropriate and not upsetting.[42]
- Relative importance: the extent to which a questionnaire item is deemed more important for the questionnaire's context of use than other items in the same content domain.
- Usability: the extent to which a system, product, or service can be used by specified users to achieve specified goals with effectiveness, efficiency, and satisfaction in a specified context of use.[46]

Figure 1. Flowchart of the development and validation procedure. EORTC QLQ-C30: European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire; ESM: experience sampling method; FACIT-Pal: Functional Assessment of Chronic Illness Therapy—Palliative Care; IPOS: Integrated Palliative Care Outcome Scale.



Ethical Considerations

This study was approved by the central ethics committee of university hospital Brussels (Belgian Unique Numbers: 1432021000533 and 1432023000043) and by the local committee of general hospital Aalst, Belgium. All participants provided written informed consent before study participation. Patients did not receive any compensation. Health care professionals received a €25 (US $27.06) gift card. Data were treated confidentially and were strictly analyzed in a deidentified form.

Participants and Setting

For the first 2 rounds, we planned to interview 32 patients and 8 health care professionals from 1 university hospital and 1 regional hospital in Belgium. These sample sizes adhere to the COSMIN and EORTC guidelines.[31,42] In the third round, we aimed to include 8 patients from the former university hospital [47] and 4 additional patients if, after the previous usability interviews, large changes would be made that would require further testing. JG and the hospital staff identified eligible patients through clinic appointment lists, and JG invited patients to participate via telephone or in-person communication during hospital visits. Health care professionals were identified through the research team's professional networks and contacted via email.

Inclusion criteria included the following: (1) a diagnosis of stage III or IV lung cancer or stage IV breast cancer; (2) patient aged ≥18 years; (3) patient spoke and understood the Dutch language; and (4) patient assigned an Eastern Cooperative Oncology Group performance status of 0, 1, or 2, based on the assessment by their treating physician.

Exclusion criteria included the following: (1) patient having major communication difficulties or insufficient cognitive abilities to take part in a semistructured interview (as judged by their treating physician); (2) patient having any psychiatric disorder that, in the opinion of their treating physician, might hinder participation due to expected burden or unreliable responses; (3) patient having uncorrectable hearing or poor vision; or (4) patient had participated in a previous part of this study.

We aimed to include 4 equally sized subgroups based on the primary tumor site (breast or lung cancer) and age (<70 years or ≥70 years).[48,49]

As for health care professionals, we aimed to include a specialist in respiratory oncology, an oncologist specialized in breast cancer, a radiotherapy specialist, an oncology nurse, an onco-psychologist, a health sciences researcher, and 2 specialist palliative care providers (i.e., a physician and a nurse affiliated with a palliative home care team).

Measurement Instruments and Procedures

Initial Item Set

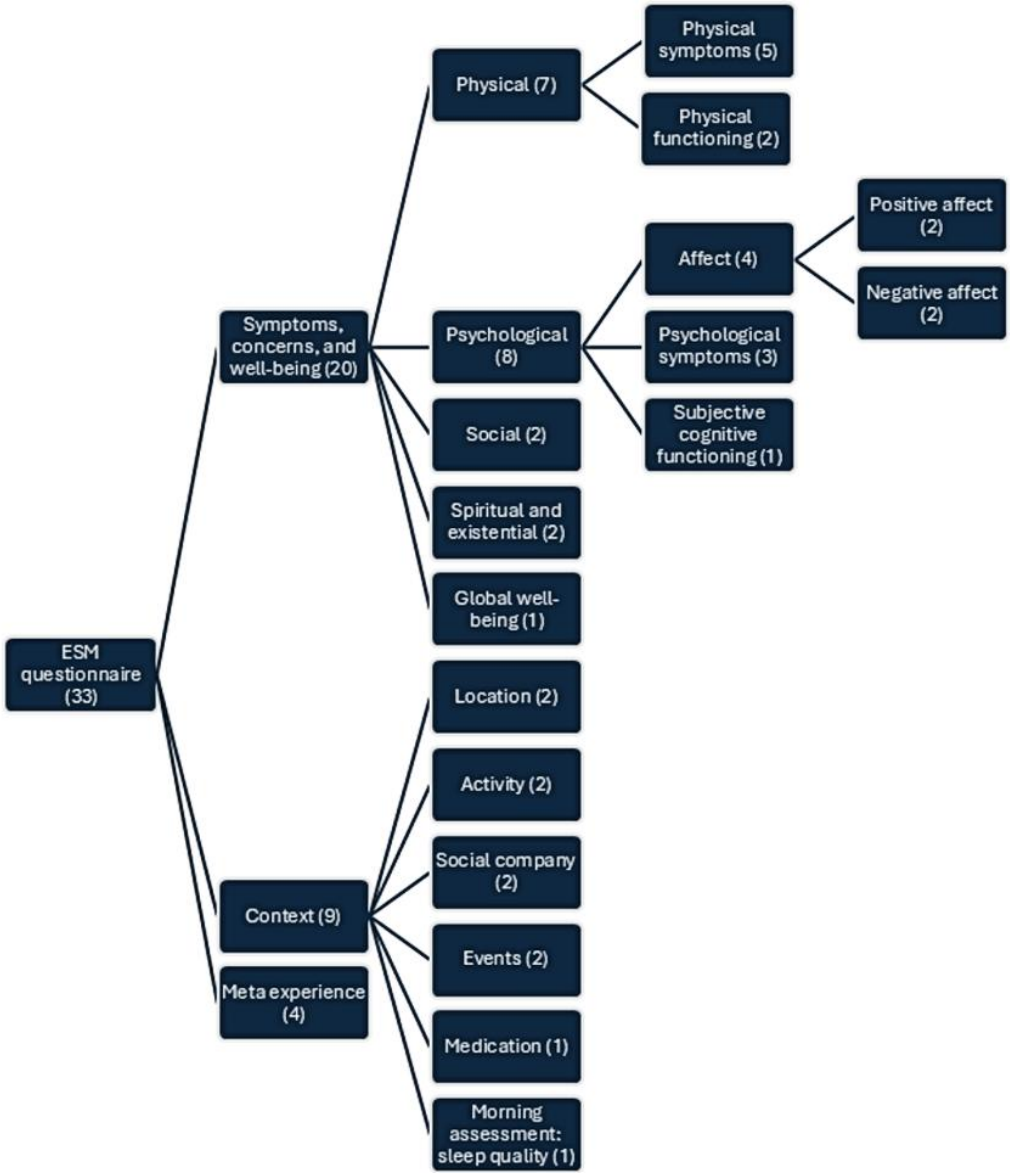
The questionnaire aimed to comprehensively measure and evaluate daily experiences of people with advanced cancer and the context in which they occur. More specifically, we conceptualized daily experiences as symptoms, concerns, and well-being across physical (including physical symptoms and functioning), psychological (including positive and negative affect, psychological symptoms, and cognitive concerns), social, spiritual-existential, and global well-being domains (Figure 2). Context was conceptualized as the person's current location, activity, social company, substantial events, medication use, and sleep quality.

We created an initial item set capturing in-the-moment experiences based on (1) the items of questionnaires identified in the 2018 review of PROMs in patients with advanced cancer by van Roij et al[1] and (2) an existing ESM item repository from the field of mental health sciences.[50] From the review by van Roij et al,[1] we selected 3 questionnaires: the European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire (EORTC QLQ-C30), Functional Assessment of Chronic Illness Therapy—Palliative Care (FACIT-Pal), and the Integrated Palliative Care Outcome Scale,[51–53] as they relate to our target population, have sufficient content validity, and have a comprehensive symptom coverage (i.e., did not focus on one specific symptom or experience). On the basis of the consensus achieved through discussion among the authors, we excluded overlapping items and items with low expected intraday variability (e.g., "I have family members who will take on my responsibilities") and retained 43 items suitable for the measurement of symptoms, concerns, and well-being across various subdomains (Figure 2). When consensus was required for adding, changing, or removing items, the content was first discussed primarily among JG, LP, and LVdB, who are all trained psychologists. LP and LVdB have >10 and 20 years of experience as end-of-life researchers, respectively. JG had 1 year of prior expertise in ESM mental health research. If further discussion or advice was needed, other authors were consulted, including a research assistant (LR; no prior expertise), a medical oncologist (EN; 7 years of experience), a health psychology researcher with experience in ESM research (GC; ≥30 years of experience), and a radiation oncologist (MDR; ≥20 years of experience).

From the ESM item repository, we purposively selected 12 items measuring affect, spanning across the valence and arousal dimensions[54] (i.e., levels of pleasantness and physiological activation, respectively), and 13 items measuring context. We additionally selected items to measure the patient's experience while completing the ESM questionnaire

(i.e., meta-experience items). We obtained official Dutch translations for all items and rephrased them to reflect in-the-moment experiences (e.g., changing "During the past 7 days, I felt..." to "In this moment, I feel..." or "Since the last beep, I felt..." with "beep" referring to the assessment prompt). For less frequent experiences or events, such as, for the item "I have had diarrhea," we used the phrase "Since the last beep" instead of "In this moment." One item measuring sleep quality was adapted from the FACIT-Pal questionnaire[52] and used for the first assessment of the day (i.e., "Last night, I slept well"). All English translations of items presented in this paper are phrased analogous to their existing PROM counterparts, or if no such counterparts were available, we provided translations of the Dutch versions used in this study.

Figure 2. Subdomains that the Experience Sampling Method for People Living With Advanced Cancer (ESM-AC) questionnaire intended to cover. Note that the between-bracket numbers after each domain name indicate the approximate number of items that we aimed to retain per domain and the number of most important items that participants had to choose for each right-most subdomain.



Content Validity and Usability Assessments

In all study rounds, we conducted individual semistructured interviews with patients with advanced breast or lung cancer. One round also included interviews with health care professionals, as outlined in Figure 1. These interviews served to assess content validity, to shorten the initial item list and divide it into a core and supplementary set, and to optimize the digital ESM questionnaire based on its usability. At the start of all interviews, the patients completed a baseline questionnaire on sociodemographic and clinical characteristics (age, gender, living situation, marital status, education level, employment status, religious denomination, and received treatments). In round 3, the baseline questionnaire additionally assessed cognitive concerns [55] and smartphone use.[56,57] We conducted all interviews in person, either at patients' homes or in quiet hospital rooms. Patients' friends and relatives were allowed to be present during the interviews. Across rounds, we introduced the ESM to participants as a digital diary on a smartphone device that uses 10 assessments per day for several consecutive days to study people's symptoms, concerns, well-being, and daily situations as well as their fluctuations within and across days.

During round 1, JG interviewed patients and health care professionals to evaluate the relevance and comprehensiveness of symptoms, concerns, and well-being items. We aimed to create a core item set of 33 items, which was the foreseen number of items needed to cover all subdomains, and a supplementary set with no item limit and aimed to improve its comprehensiveness by adding items deemed relevant but missing by the participants. Participants were asked to verbally rate each item's relevance ("not at all," "a little," "quite a bit," and "very much"), select the most important items for each subdomain (Figure 2 displays the number of items to select per subdomain, as instructed by the interviewer), suggest missing concepts, and mark inappropriate items. Participants were prompted for reasons for categorizing items as inappropriate or "not at all" or "a little" relevant.

In round 2, JG interviewed patients on the comprehensibility of items resulting from the first round (as the last part of content validation), the relevance and appropriateness of newly added items, and the appropriateness and comprehensiveness of context and meta-experience items and their response options (assessed analogous to round 1). To assess comprehensibility, patients completed a pen-and-paper questionnaire while thinking out loud.[58]

In round 3, JG and LR conducted interviews to assess and optimize the ESM questionnaire's usability by letting patients respond to it in the m-Path app.[45] m-Path is a web-based platform that provides "an intuitive and flexible framework to conduct smartphone-based

ecological momentary assessment and intervention studies...".[45] Patients were each provided with a Motorola E20 smartphone device (Motorola Mobility LLC) with the digital ESM questionnaire available in the m-Path app. They were instructed on how to use the app and asked to complete the digital questionnaire on the provided device while thinking out loud. The researcher prompted patients when difficulties were observed (e.g., difficulties answering certain ESM questions). Afterward, a brief semistructured interview assessed the usability of the questionnaire through an adapted version of the System Usability Scale (5-point Likert scale; 1=totally do not agree and 5=totally agree).[59,60] Usability outcomes included readability, comprehensibility, ease of use, reasons for encountered difficulties, and expected burden of receiving 10 assessments per day for 6 days. Finally, patients completed the digital ESM questionnaire a second time without thinking out loud to estimate completion times. All interviews were recorded and transcribed verbatim. More details on procedure and instruments for this round have been reported in the study protocol.[61]

Data Analyses and Continuous Adaptations of the Questionnaire

Following the EORTC guidelines for module development, as applied by Groenvold et al,[44] we transformed item relevance ratings into a 0 to 100 scale, with "not at all" corresponding to 0 and "very much" to 100. We calculated mean relevance scores and SDs per item. In addition, we calculated the percentages of respondents who rated an item as inappropriate or upsetting, who listed an item among the top *n* most important items per subdomain (*n* was the approximated number of items to retain in the final questionnaire for each subdomain; Figure 2), and who found an item incomprehensible. We calculated descriptive statistics for usability.

Using conventional content analysis[62] on the interview transcriptions, we inductively developed content categories for participants' reasons of lack of item relevance (provided by participants who judged an item as "not at all" or "a little" relevant), inappropriateness, problems with comprehensibility, and themes of novel items to add.[62] We added items to the list if at least 2 participants suggested adding it to the questionnaire. Furthermore, we developed content categories for difficulties or conveniences in the user experience or comprehension of the digital questionnaire.

The questionnaire was adapted after each of the 3 rounds. After round 1, we used descriptive statistics of relevance, importance, and appropriateness ratings from the patients and health care professionals to guide item exclusion and categorization into core and supplementary sets (refer to Supplementary Material 1 for an overview of the categorizations). We assigned items to the core item set if they ranked among the top *n*

most important per subdomain (refer to Figure 2 for n values), were judged "quite a bit" or "very much" relevant by half of the participants (50%), and were deemed appropriate (or amenable to rewording). For the removal of items, the authors discussed the participants' reasons for low relevance of items that were rated as "not at all" or "a little" relevant by at least half of the participants, or of items for which the participants provided recurring reasons for lack of relevance or the inappropriateness of items and the item could not be appropriately reworded or changed to resolve those reasons. Items that were not removed or categorized into the core set were assigned to the supplementary set. Note that the decision to use the core and supplementary sets was made after analysis of round 1.

After round 2, we made necessary and feasible item revisions based on the descriptive statistics of comprehensibility and inappropriateness and on the content categories for reasons of items' low comprehensibility and inappropriateness.

After round 3, we used descriptive statistics of usability outcomes and content categories of difficulties when using the digital questionnaire to improve the usability of the questionnaire in m-Path. Following general recommendations in ESM research,[16,63] we used a mean questionnaire completion time threshold of 3 minutes to determine whether the questionnaire was considered too long.

Results

Participant Characteristics

In round 1, a total of 15 patients and 8 health care professionals participated; in round 2, a total of 18 new patients participated; and in round 3, a total of 10 new patients participated (Table 1). The overall mean age was 67.3 (SD 10.3) years. Overall, 23 (53%) of the 43 patients had a stage III or IV lung cancer diagnosis, and the remaining 20 patients (47%) had a stage IV breast cancer diagnosis. Close others were present during 4 interviews in round 1, seven in round 2, and seven in round 3.

Table 1. Sociodemographic and clinical characteristics of patients per interview round

Characteristics	Round 1 (N = 15)[a]	Round 2 (N = 18)[b]	Round 3 (N = 10)
Age (years)			
M (*SD*)	68 (8.5)	68.7 (11.3)	63.8 (11.1)
Range	56-78	44-86	45-78
Gender [n female(%)]	11 (73%)	14 (78%)	6 (60%)
Living situation (n)			
Home, alone	2	4	2

Characteristics	Round 1 (N = 15)[a]	Round 2 (N = 18)[b]	Round 3 (N = 10)
Home, with partner/children/other	13	14	8
Marital Status (n)			
Married	13	8	-
Living together, but not married	0	6	-
Widowed	1	1	-
Divorced	1	3	-
Educational level (n)			
Primary	2	0	1
Secondary	8	10	4
Tertiary	5	8	5
Employment status (n)			
Professionally active	2	1	1
Not professionally active	13	17	9
Religious denomination (n)			
Catholic Christian	6	8	6
Not religious	5	9	4
Not specified	4	1	0
Cancer diagnosis			
Stage III or IV lung cancer	7	10	6
Stage IV breast cancer	8	8	4
Treatment(s) received, as reported by patient			
Chemotherapy	14	13	9
Radiotherapy	13	10	5
Surgery	12	3	7
Hormonal therapy	4	5	2
Immunotherapy	6	9	4
EORTC QLQ-C30 concentration problems (n)	-	-	
Not at All			7
A Little			2
Quite a Bit			1
Very Much			0
EORTC QLQ-C30 memory problems (n)	-	-	
Not at All			5
A Little			3
Quite a Bit			2
Very Much			0
Smartphone ownership in years, *M* (*SD*)	-	-	10.2 (4.4)
Daily time spent on smartphone in hours, *M* (*SD*)	-	-	3.2 (2.8)
Confidence using smartphone (1 = "Not at all confident", 5 = "Very confident"), *M* (*SD*)	-	-	4.1 (0.7)

Abbreviations. M = mean, *SD* = standard deviation

[a]Due to an oversight, we did not collect participation rates and reasons for non-participation in this round.

[b]Out of 25 invited patients. Reasons for non-participation included no interest, as indicated by patient or partner (n = 5), inability to find an appropriate interview location (n = 1), experiencing distress (n = 1), or no reasons provided (n = 1).

The following sections present the results per interview round and relevant adaptations made to the ESM questionnaire based on these findings.

Interview Round 1

Relevance

Most items received positive relevance ratings, with no unanimous low relevance ratings across all participants (Supplementary Material 2). The most frequent reasons for considering an item lacking in relevance were overlapping content with other items, not experiencing the measured construct, not perceiving the measured construct as bothersome, and thinking the item could be phrased better. After discussion among the research team, we removed 12 items that at least half of the participants rated as having "a little" relevance or less or that participants noted had considerable overlapping content with other items. For instance, we removed the item "At this moment, I feel sick" due to overlap with specific symptoms such as nausea and removed the item "At this moment, I feel capable of making decisions" due to low reported relevance because patients reported not having to make decisions.

Some items were considered irrelevant by the participants because they measured stable constructs within a day. To address this, we deviated from the planned approach to develop in-the-moment items only and instead developed several items for designated morning and evening assessments. We dedicated 1 item of the initial item list to morning assessments and 11 to evening assessments. For instance, the in-the-moment item "At this moment, I feel moral support by my close ones" was revised to the evening item "Today I felt supported by others." Items excluded before round 1 based on little expected within-day variability were reconsidered for inclusion in the once-daily questionnaires. Hence, we added 8 initially removed items to the evening list for further testing in round 2 (eg, "Today, I was able to openly discuss my concerns with my close ones").

Appropriateness

Out of 55 items, 22 (40%) were deemed inappropriate by between 1 and 5 participants (Supplementary Material 2), with 12 (22%) items deemed inappropriate by at least 2 participants. Reasons included privacy concerns, content overlap, confronting questions, infrequent experiences, question formulation, clinical utility, and bad subdomain fit (Supplementary Material 3). We removed the most inappropriate item "At this moment, I

feel enthusiastic" as 4 patients and 1 health care professional marked it as inappropriate due to content overlap and patients not experiencing this feeling.

Comprehensiveness

Participants suggested adding several constructs to improve comprehensiveness, leading to the addition of 13 items to the item list (Supplementary Material 4). Among these, 2 were conditional items administered only if certain responses are given during the same assessment, such as reporting moderate pain levels or poor sleep. These questions included "The pain is located in these parts of the body: ..." and "I think I didn't sleep so well, because: ... ." Examples of other added items included "At this moment, I feel capable of working" and "At this moment, I have negative thoughts or feelings." In addition, we included 3 items in the questionnaire as the research team thought them to be necessary for comprehensive measurement of the psychological domain ("At this moment, I feel restless" and "At this moment, I feel depressed") and an open question concerning other contextual factors ("If there is anything else you want to mention about the period since last beep, you can do that here:").

Relative Importance

We assigned 46 items with the highest relative importance of their subdomain to the core questionnaire and 38 items to the supplementary list (refer to Supplementary Material 2 for the proportions of how many times items were chosen as among the top most important).

Interview Round 2

Comprehensibility

Between 1 and 5 participants provided remarks for 31 (39%) out of 79 items (Supplementary Material 5). Reasons for marking items as incomprehensible included unclear word meanings, different interpretations from the intended meaning, situational content, response options misalignment, and other issues. In response to this feedback, we changed the wording of some items and response options and removed some items (Supplementary Material 6). For instance, we replaced the response option "On the move" under the item "What am I doing?" to "En route (eg, on the bus)" for clarity. Another example is the core questionnaire item "Today I felt supported by others," which we changed to "Today I received the support I needed from my loved one(s)" because some patients indicated not needing or seeking support all the time.

Relevance of Added Items

On average, most added items were rated as at least "a little" relevant, with mean ratings typically exceeding "quite a bit" relevant (Supplementary Material 2).

Appropriateness of Added Items

No items were considered as inappropriate by the participants.

Additional Findings and Changes Made

Three patients reported frequently experiencing muscle cramps, leading to the addition of the item "Since the last beep, I had muscle cramps" to the supplementary list. On the basis of research team consensus, we improved the comprehensiveness of the "Where am I?" item by adding an "outside" response option. Figure 3 displays the resulting questionnaire in the m-Path app.

Figure 3. Screenshots of the Experience Sampling Method for People Living With Advanced Cancer questionnaire in the m-Path app. Left: receiving a notification, middle: example of the slider response scale; right: example of the multiple-choice response scale.

Interviews Round 3

Usability

On a scale ranging from 0="completely disagree" to 5="completely agree," participants generally expressed positive sentiments about using the ESM-AC questionnaire in their

daily lives (mean 3.6, SD 0.8), finding it easy to use (mean 4.5, SD 0.5), and expecting no need for support with the questionnaire or the smartphone device in their daily lives (mean 1.6, SD 0.7 and mean 1.5, SD 0.7, respectively). They also indicated that there was no inconsistency in the questionnaire (mean 1.6, SD 0.7). They expected that most people would quickly learn to use the questionnaire (mean 4.0, SD 1.1), felt confident using it (mean 4.2, SD 1), did not require a lot of knowledge to complete it (mean 1.3, SD 0.5), items and response options were clear (mean 4.3, SD 0.5 and mean 4.0, SD 0.9; respectively), the response options were comprehensive (mean 4.1, SD 1), and the lay-out was satisfying (mean 4.2, SD 0.6). Moreover, participants did not experience it as burdensome to complete the questionnaire (mean 1.5, SD 0.7) and did not think it was too long (mean 1.9, SD 0.9). However, as reflected by neutral mean scores with higher variance, participants were more divided regarding the simplicity of item phrasings (mean 2.2, SD 1.2) and the readability of items (mean 3.9, SD 1.4). Moreover, most participants anticipated that completing the questionnaire 10 times per day on 6 consecutive days would be burdensome (mean 3.7, SD 1.1).

Perceived Difficulties

Participants reported various barriers with using the digital ESM-AC questionnaire and device, and we observed some difficulties when participants used the questionnaire. For some patients, response formats and the option to skip open-ended items were initially not clear, the momentariness of items (i.e., "At this moment, I feel...") required further instructions (e.g., participants would give higher pain scores due to previous pain episodes, when currently not experiencing pain), interpretations of some complex items were unintended (e.g., concentration problems were interpreted as wider cognitive problems), the purpose of the intensive assessment schedule of the ESM study and of specific questionnaire content domains were unclear (e.g., context items), and the device went into standby mode during the interview. All the changes made to the ESM-AC questionnaire, smartphone device settings, and onboarding instructions are reported in Table 2. Refer to Supplementary Material 7 for the resulting core ESM questionnaire. We also created a manual for researchers to provide patients with instructions where needed (Supplementary Material 8).

Table 2. Changes made to different ESM-AC questionnaire properties after the usability interviews of round 3.

Property	Observed or reported barriers	Changes made
ESM Questionnaire	Momentariness of item unclear	The phrasing "at the moment the beep went off" was added to the multiple-choice context items. For example: "Who am I with?" → "Who was with me at the moment of the beep?"
	Momentariness of item unclear	In-the-moment phrasings were added to items that did not previously include it. For example: "I'm in bed or on the couch" → "I was in bed or sofa when the beep went off"
	Meaning of "place I was at" wrongly associated with bed or sofa	"I was happy with the place I was at" was reordered to be between "Where was I at the moment of the beep?" and "I was in bed or sofa when the beep went off"
	Unclear what was measured with substance item	"Since last beep, I have used the following" → "Since last beep, I have used the following substance(s)" (response option "Other" was changed to "Other substance(s)")
	-	An m-Path feature was selected for the multiple-choice items that allows participants to directly type new categories when the "other" option is selected. This replaced the need for conditional open-ended items when participants used the respective response option.
Smartphone device settings	Device screen darkened while completing the questionnaire	The time-to-standby settings on the devices was changed from 30 seconds to 60 seconds.

Property	Observed or reported barriers	Changes made
Onboarding instructions	Response formats and option to skip open-ended items were not initially clear; momentariness of items required instructions; unintended interpretations of some complex items; purpose of the intensive assessment schedule of the ESM study and of some study domains (e.g. context items) unclear; reported expectations of missing assessments; difficulty unlocking smartphone	A formal interview guide was developed for the training at the onboarding session, which included instructions on how to explain the different response option formats and how to use them, skipping open-ended items, temporality of questions (i.e. in-the-moment, since last beep), content of more complex items (e.g. concentration as separate from memory problems), the purpose of the intensive assessment schedule of the ESM study and of some question domains, acceptability of missing assessments, unlocking the smartphone.

Completion Times

During the second time of filling in the digital ESM-AC questionnaire (ie, without thinking out loud), it took participants on average 3.8 (SD 1.1) minutes to complete the questionnaire of 25 to 31 items (depending on the number of triggered conditional items).

Discussion

Principal Findings

We developed, content validated, and optimized the ESM-AC questionnaire, a digital ESM questionnaire covering multidimensional domains to capture the experiences of people with advanced breast or lung cancer. Overall, the patients found the questionnaire items comprehensible and appropriate and had positive views toward using the questionnaire in the m-Path app. As all items in the initial set were relevant to at least some patients, we primarily used the perceived importance of the items to categorize them into a core questionnaire for use with all patients and a supplementary item set from which patients can select items to tailor the ESM questionnaire to their needs and experiences.

As a novel and promising tool to assess patients' symptoms, concerns, and overall well-being, the ESM-AC questionnaire supplements the existing measurement methods in oncology, a field that has traditionally relied on retrospective PROMs.[1–3] The ESM uniquely allows for the measurement of experiences in real time within the patient's everyday life.[16] By using multiple assessments per day, it enables the investigation of how these experiences change and unfold over time, including their correlations and temporal relationships.[16] The repeated within-day assessments of the ESM can also supplement more traditional daily diary measures in oncology that assess patients once per day to uncover fine-grained fluctuations of symptoms. This can be important to better understand the complexity and dynamics of patient experiences from a research perspective. Moreover, from a clinical perspective, the ESM can be used to improve understanding of symptoms or concerns of individual patients identified using traditional once-daily or weekly administered PROMs.

To the best of our knowledge, the ESM-AC questionnaire is the first of its kind in oncology in several respects. First, the limited number of ESM studies in populations with cancer have never determined the content validity of their questionnaire items to be assessed in a repeated in-the-moment context.[9,13] Second, in cancer ESM research, the ESM-AC questionnaire is among the first to incorporate items on context and context appraisal.[9,12] By including items on concurrent location, activity, and social company, it will be possible to better understand fluctuating symptoms and their interactions with contextual factors. ESM research in other fields has shown how different contexts such as social company, concurrent activities, and location can influence patients' mental and physical experiences.[64–66] Third, by dividing items into a core and supplementary list, item selection can be adapted or tailored to a particular patient or a population of patients, that is, by adding relevant supplementary items such as "At this moment, I feel capable of working." This makes our ESM measurement highly relevant for people with advanced breast or lung cancer.

Using the m-Path app,[45] results showed that the ESM-AC questionnaire was easy to use for all patients, and the patients had positive views toward the questionnaire presented on the device. This is crucial because it is important to minimize the potential burden of frequent daily assessments. This is especially true when working with populations that may be more likely to experience increased symptoms and reduced physical functioning related to cancer and related treatments. In addition, although the questionnaire took, on average, longer than the generally recommended 3 minutes' completion time in ESM research,[16,63] participants indicated that it was not too long. Therefore, we deviated from our initial 3-minute threshold and did not further shorten the questionnaire.[61] As we purposively sampled people aged >70 years and <70 years (mean 63.8, SD 11.1; range 45-78 years),

we were able to conclude that the system questionnaire was usable for older age groups (i.e., those aged ≤78 years) that are typically thought to have less smartphone experience, as indicated by their positive views on usability of the system.

Implications for Future Research

The next step in the development of the ESM-AC questionnaire is to evaluate it in a detailed pilot ESM study. Such a study needs to evaluate the optimal number of daily assessments among people with advanced lung cancer or advanced breast cancer. As most participants indicated that they expected 10 assessments per day for 6 consecutive days, as is often used in ESM research,[16] to be potentially burdensome, the burden of completing such an intensive assessment schedule should be carefully investigated in real life. This burden needs to be weighed against the necessary resolution to measure change in the construct of interest. In addition, further research is needed regarding the acceptability of the questionnaire length and clarity of the instructions, items, and response options if researcher help is not immediately available. If further research confirms the feasibility and optimal features for a larger-scale ESM study, this will pave the way toward a substantial improvement of our knowledge of how symptoms, concerns, and well-being across multiple domains fluctuate in the everyday life of people with advanced breast or lung cancer.

Researchers aspiring to apply similar methods to other populations with cancer or serious illness are encouraged to further adapt the methods to their target population. We recommend the ESM-AC questionnaire as a starting point for adaptations toward the target population and context. The core ESM questionnaire can be used in its entirety or researchers can select the domains of interest, possibly supplemented by items selected from the supplementary item set. Determining the questionnaire's content validity through semistructured interviews will help to optimize and ensure its relevance, comprehensiveness, and comprehensibility for intended research.

Furthermore, ESM data can be compared to retrospective patient-reported outcome data to confirm and obtain more evidence on the added value of the ESM and the different experiences it captures and to investigate the ecological validity of such data. Another important area of future ESM research in oncology can be to explore its clinical value and utility, for instance, by providing clinicians with time-series visualizations of their patients and comparing these with information gathered through traditional consultations.

Strengths and Limitations

This study is among the first studies to test the content validity of an ESM questionnaire in any scientific field and has resulted in the first content-valid ESM questionnaire in the field of oncology, thereby answering to recent calls for more questionnaire validation in ESM research.[9,12,13] This study has several strengths. First, it involved close collaboration with people with cancer and health care professionals in multiple phases of questionnaire development, ensuring its relevance for the target population. Second, relevance was further ensured by adapting items from existing validated PROMs.[51–53] Moreover, unlike many quantitatively focused questionnaires in ESM research, the use of a free-text response item "If there is anything else you want to mention about the period since last beep, you can do that here:" allows us to study any relevant experiences that are currently missing in the core questionnaire. Third, we included an equal number of patients aged <70 years and >70 years, ensuring the inclusion of the latter as an often underrepresented group in cancer studies. Finally, this study's relatively good participation rate reduces the risk of selection bias.

Several limitations should be noted. First, the study was limited to Dutch-speaking patients from 2 study sites, possibly limiting the extent to which the ESM-AC questionnaire's content validity can be generalized to patients with sociodemographic characteristics different from our sample. However, the ESM questionnaire will be further tested among new patients recruited from different hospitals. Second, the relatively high functional status of patients in our sample (i.e., Eastern Cooperative Oncology Group scores between 0 and 2) may lead to limited generalizability of the results to patients with advanced cancer who have more functional limitations. Third, as no people aged >78 years participated, the usability of our ESM is unknown for older populations. Fourth, we did not record whether patients were actively receiving treatment, thereby preventing more detailed insight into the sample's current perspectives and experiences. Finally, due to the study design, we were not able to test how health care professionals viewed the relevance and how patients and health care professionals viewed the relative importance of evening assessment items that that were initially removed by the authors based on their low expected within-day variability.

Conclusions

We successfully developed the ESM-AC questionnaire, the first content-valid digital ESM questionnaire in oncology to study the daily experiences of people with advanced breast or lung cancer in their everyday environments. If the method proves feasible in future research on advanced cancer and in other patient groups, it paves the way toward gaining

novel insights into the daily lives of patients with cancer, possibly informing and facilitating patient-centered care.

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Authors' Contributions

The study was conceptualized by LVdB, MDR, LP, and JG. Data were curated by JG and LR. Formal analysis, software, and visualization were performed by JG. LVdB, MDR, and LP were involved in funding acquisition. Investigation was conducted by JG and LR. Methodology was conducted by JG, LP, EN, GC, MDR, and LVdB. LP, MDR, and LVdB provided supervision and validation. The original draft was written by JG, LP, and LVdB, and reviewing and editing were done by LR, EN, GC, and MDR.

Conflicts of Interest

None declared.

Supplementary Materials

Supplementary Material 1: Figure on the criteria for categorization into the core questionnaire, supplementary set or items to be removed.
Supplementary Material 2: Inappropriateness frequencies, relevance means, and proportions of relative importance ratings of experience sampling method items.
Supplementary Material 3: Frequency table of the categorized reasons for deeming an item inappropriate.
Supplementary Material 4: Content categories of patient and health care professional responses to the open-ended question on what content was missing from the item sets.
Supplementary Material 5: Proportions of participants who had no difficulties with comprehensibility of item per item, ordered by subdomain.
Supplementary Material 6: Resulting Dutch item versions before and after the first two interview rounds.
Supplementary Material 7: Final core the ESM-AC (Experience Sampling Method for People Living With Advanced Cancer) questionnaire.
Supplementary Material 8: Dutch onboarding session manual created after interview round three.

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PART III

EVALUATION OF ESM

CHAPTER 4

Investigating experiences of people with advanced breast or lung cancer in their natural context: protocol for an experience sampling study

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Abstract

Introduction

People with advanced cancer can experience a wide range of multidimensional symptoms or concerns, but little is known about when and how these fluctuate in daily life. Experience sampling methods (ESMs) involve repeated self-reports in people's natural contexts aimed at uncovering everyday life experiences. ESM has limited recall bias and good ecological validity but might be burdensome to patients. This study aims to pretest and evaluate the feasibility and clinical utility of a validated ESM and use it to explore everyday experiences of people living with advanced breast or lung cancer.

Methods and analysis

In step 1, we will optimise our ESM method by pretesting it through usability interviews and a pilot ESM study. In step 2, we will evaluate and use the ESM method through an observational ESM study to investigate the daily experiences of people with advanced breast or lung cancer. Step 2 also includes interviews with healthcare professionals to determine the clinical utility of ESM in oncology. Participants will complete a digital questionnaire ten times per day, measuring momentary experiences in the physical, psychological, social, spiritual-existential domains and context. Multilevel regression models will analyse fluctuations and temporal relations among measured experiences and context. Analyses also include evaluation of compliance and participation rates. We will apply content analysis to the usability interviews and follow-up interviews of the pilot ESM study.

Ethics and dissemination

We obtained approval from the ethics committees of the University Hospitals of Brussels (BUN: 1432023000043) and Ghent (ONZ-2023-0136). Results will be published in open-access, peer-reviewed journals and presented at conferences. If ESM appears feasible in this population, it could offer new insights into the daily experiences and help optimise support for people with advanced cancer.

Introduction

This study aims to uncover the potential of experience sampling methods (ESMs) for understanding symptoms and problems experienced by patients with advanced cancer. Increased efficacy of cancer treatments has led to a rising global population of people living with advanced cancer.[1,2] Despite effective strategies to reduce side effects of treatments, many people with advanced cancer experience an array of physical symptoms such as pain, fatigue or dyspnoea,[3,4] but also psychosocial[5] and spiritual or existential concerns.[6,7] However, as most available instruments (e.g., patient-reported outcome measures or PROMs) assess these problems and concerns retrospectively over the previous days or week,[8] there is currently limited temporal fine-grained understanding of how these symptoms or concerns occur and fluctuate in the context of daily life. Gaining knowledge on the everyday experiences of patients with cancer is vital for improving patient-centred care, as it offers a comprehensive view of patients' daily lives and could lead to treatment optimisation (e.g., due to higher sensitivity in detecting adverse effects)[9] and identification of possible intervention targets.

To address this gap, one promising solution is offered by ESMs, also known as ecological momentary assessment (EMA).[10] ESM involves repeatedly gathering self-report data from participants in their daily lives, often using mobile technologies such as smartphones. ESM offers several advantages over 'traditional' measures of symptoms and concerns that rely on recall over a given preceding period.[11,12] First, ESM offers the ability to study fine-grained temporal variability of experiences by measuring the same concept multiple times per day, for several consecutive days.[13] Second, ESM limits recall biases as items are presented in the moment, not requiring the individual to recall or aggregate information over larger periods of time.[14] Third, ESM improves ecological validity by measuring experiences in natural contexts[14] and considering contextual factors such as current activities or social company. These advantages make ESM particularly useful for studying people's daily experiences and a unique addition to the so-called internet of medical things, as it can supplement current passive monitoring strategies in telemedicine with data on real-time patient-experienced symptoms, concerns and well-being.[15] Moreover, these advantages have helped to establish ESM in mental health and psychosomatic research, as it provides a valid way to disentangle the multiple different determinants of psychopathology or psychosomatic symptoms and develop workable and personalised treatment targets.[13,16] We expect that ESM could provide the same opportunities in the context of oncology, for instance, for the treatment or management of fatigue or other physical or psychological symptoms.

Recent literature reviews found only a limited number of studies that used ESM to study experiences of people with cancer.[17,18] One review[18] found only three ESM studies exclusively focused on advanced cancer and were limited in certain methodological considerations, such as not including contextual items to account for the individual's current context.[19–21] Optimal study conditions remain unclear from this limited body of work.[18] This highlights the need for more methodological development and testing, especially for people at an already increased risk for symptom burden, such as people with advanced cancer (i.e., stage IV).[18,22,23] As ESM is a novel method to be developed and evaluated in people with advanced cancer, the publication of this protocol strives to inform and inspire other researchers on the development of ESM questionnaires and study designs.

In this study, we aim to test the feasibility and clinical utility of an ESM questionnaire for people with advanced cancer. In previous work,[24] we have developed and validated a questionnaire to assess daily experiences across physical, psychological, social and spiritual-existential domains, as well as the context in which they occur among patients with advanced cancer (i.e., stage IV breast or stage III or IV lung cancer). The questionnaire will be administered digitally through a mobile application designed for ESM measurements (i.e., m-Path).[25] In this study, we will pretest the digital ESM questionnaire, adapt and optimise it, and subsequently conduct an observational ESM study in people living with stage IV breast cancer or stage III or IV lung cancer.

More specifically, the pretesting phase of our ESM questionnaire (step 1) aims to optimise the ESM methods and study procedures among people with stage IV breast or stage III or IV lung cancer (Figure 1). The observational ESM study (step 2) aims to examine (a) the fluctuations and temporal relationships between patient-experienced symptoms, concerns, and well-being, and the context in which they occur, (b) the relationship between responses on the ESM questionnaire and traditional retrospective PROMs, (c) the usability, feasibility and acceptability of this (digital) ESM questionnaire in people with stage IV breast or stage III or IV lung cancer and (d) its clinical utility in people with stage IV breast or stage III or IV lung cancer for healthcare professionals working in oncology.

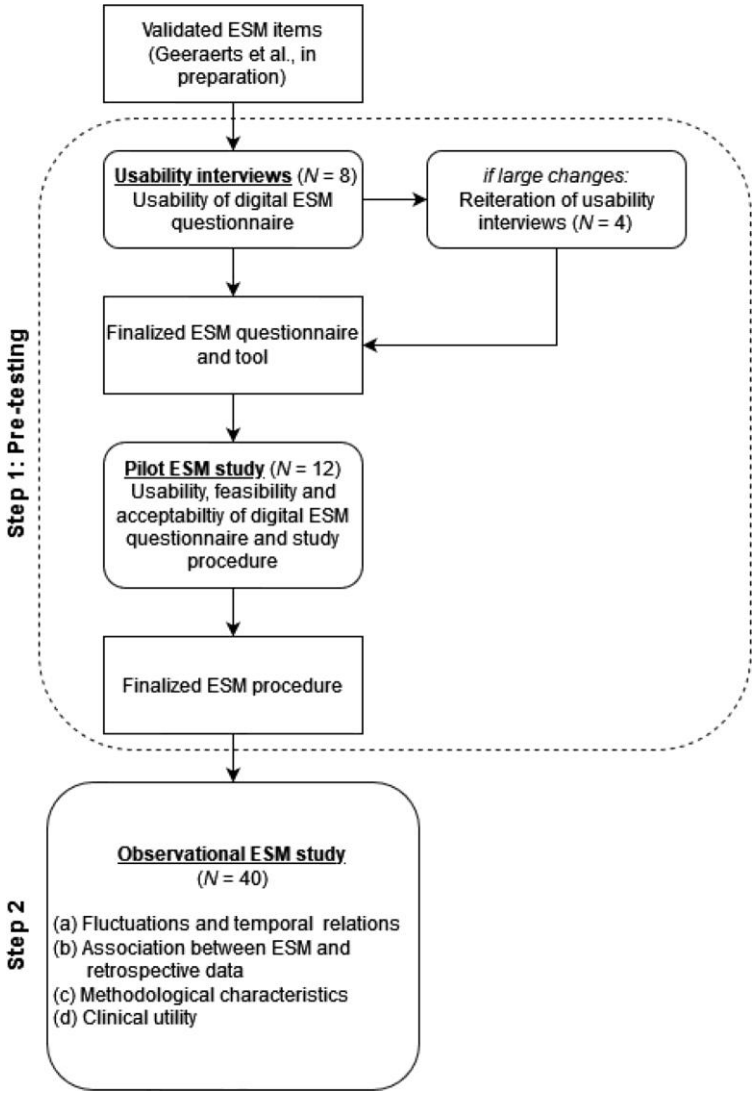
Methods

Study design

This study follows a two-step procedure (Figure 1). In step 1 (addressing research aim 1), we will pretest and optimise our ESM method and procedure by evaluating barriers and facilitators related to its usability, feasibility and acceptability through usability interviews

and a pilot ESM study. In step 2 (addressing research aim 2), we will conduct an observational ESM study and conduct interviews with clinicians on the clinical utility of ESM. This protocol is written in adherence to the Standard Protocol Items Recommendations for International Trials (SPIRIT) 2013 statement.[26]

Figure 1. Relationship between study aims, research steps and methods. ESM, experience sampling method.



Participants

Patients

The eligibility criteria for patients are provided in Table 1. We will create four equally sized subgroups of participants based on primary tumour site and age. Primary tumour site groups will be breast or lung cancer, and age groups will be younger than 70 or older than or equal to 70.[27,28] The inclusion of older adults in this study is necessary to prevent under-

representation of this group, as the mean age of participants in electronic symptom monitoring studies in oncology is typically lower than in the total cancer population,[18] potentially skewing research findings related to outcomes such as the burden by multiple assessments each day and self-efficacy of using the digital technology. Participants from previous phases of this research project will be excluded from participating in the current study.

Table 1. Inclusion and exclusion criteria for patients

Inclusion criteria All connected by 'AND'	(1) being able to fluently speak and understand Dutch; (2) being 18 years or older; (3) having a confirmed diagnosis of stage III or IV lung cancer, or stage IV breast cancer; (4) scoring 0, 1 or 2 on the Eastern Cooperative Oncology Group (ECOG) performance status.
Exclusion criteria All connected by 'OR'	(1) have major communication difficulties or insufficient cognitive abilities to take part in a cognitive interview, as judged by the treating physician; (2) have any psychiatric disorder that, in the opinion of the treating physician, makes participation in the study impossible; (3) are unable to read digital ESM questions or hear interview questions due to uncorrectable vision or hearing problems; (4) have participated in previous phases of this study.

Healthcare professionals

Healthcare professionals will be eligible for clinical utility interviews if they are the treating oncologist or oncopsychologist of a sample of consenting participants in the observational ESM study or if they are part of oncology nursing staff at the University Hospital of Brussels or Ghent.

Samples sizes

The usability interviews will be conducted with at least eight patients, and four additional patients will be interviewed if changes are made to the questionnaire based on the preceding usability interviews and are sufficiently large to require new testing. The pilot ESM study will be conducted with 12 patients. The observational ESM study will be

conducted in 40 patients, equaling 2400 scheduled assessments across 6 days. Moreover, we aim to include eight oncologists, two oncopsychologists and two members of oncology nursing staff in clinical utility interviews. Based on previous studies,[18,29–31] these numbers seem appropriate to explore the method's usability, feasibility, acceptability and clinical utility.

Recruitment setting and timing

Recruitment for step 1 is expected to run from May 2023 to June 2023 for the usability interviews and from June 2023 to July 2023 for the pilot ESM study. Subsequently, step 2, the observational ESM study, will run with recruitment up to the end of 2023. Patients will be recruited at the oncology and radiotherapy departments of University Hospital Brussel, the oncology and pneumology departments of University Hospital Ghent, through peer support groups in Flanders and Brussels, and through snowball sampling. Reasons for non-participation will be documented if patients wish to state them.

Measurement instruments

An overview of measurement instruments is provided in Table 2. All measures and interview guides to be used in this study are provided in online supplemental materials.

Table 2. Measured outcomes with their respective scales or instruments and number of items for all study phases

Study Phase	Measured Outcomes (Scale/Instrument)	Number of items
Usability interviews		
Baseline questionnaire	• Sociodemographic characteristics, • Treatment trajectory; • Cognitive functioning (EORTC QLQ-C30 sub scale[32]); • Smartphone use[33,34]	16
Think aloud procedure	• Experienced difficulties with method[a]; • Questionnaire completion times	/
Usability assessment	• Usability of ESM method (adapted System Usability Scale[35]); • Reasons for difficulties encountered (inter-view probing)[a]	17

Study Phase	Measured Outcomes (Scale/Instrument)	Number of items
Pilot ESM study		
Baseline session	• Sociodemographic characteristics, • Treatment trajectory; • Cognitive functioning (EORTC QLQ-C30 sub scale[32]); • Smartphone use[33,34]; • Attitude towards participation in scientific studies; • Levels of anxiety and depression (HADS[36]); • Activities of daily living (Barthel-Index-SF[37]); • Instrumental activities of daily living (Lawton IADL[38]); • Coping style (Brief-COPE[39])	71
ESM period	• Symptoms, concerns and well-being[24]; • Context[24]; • Experience of filling in questionnaire[24]; • Questionnaire completion times	29 to 39 items[b]
Follow-up session	• Quality of life (EORTC QLQ-C30[32]); • Subjective well-being (ACSA[40]); • Acceptability: Experience of taking part in the study[41]; • Careless responding[41–43]; • Usability of ESM method (adapted System Usability Scale[35]); • Reasons for difficulties encountered (inter-view probing)[a]	76
Observational ESM study		
Baseline session	• Sociodemographic characteristics, • Treatment trajectory; • Cognitive functioning (EORTC QLQ-C30 sub scale); • Smartphone use[33,34]; • Attitude towards participation in scientific studies;	71

Study Phase	Measured Outcomes (Scale/Instrument)	Number of items
	• Levels of anxiety and depression (HADS[36]); • Activities of daily living (Barthel-Index-SF[37]); • Instrumental activities of daily living (Lawton IADL[38]); • Coping style (Brief-COPE[39])	
ESM period	• Symptoms, concerns and well-being[24]; • Context[24]; • Experience of filling in questionnaire[24]	29 to 39 items[b]
Follow-up session	• Quality of life (EORTC QLQ-C30[32]); • Subjective well-being (ACSA[40]); • Acceptability: Experience of taking part in the study[41]; • Reasons for difficulties encountered (inter-view probing)[a] Careless responding[41–43]	59
Clinical utility interviews[c]	• Experience with monitoring tools and compu ter technology[44,a]; • Reflections on ESM data visualizations[44,a]; • Reflections on the purpose of ESM in onco logy[44,a]	28 (interview questions)

Abbreviations: ESM, Experience Sampling Methods; EORTC QLQ-C30, European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30; HADS, Hospital Anxiety and Depression Scale; Barthel-Index-SF, short version of Barthel Index; Lawton IADL, Lawton Instrumental Activities of Daily Living; Brief-COPE, Brief Coping Orientation to Problems Experienced; ACSA, Amnestic Comparative Self-Assessment

[a]Qualitative data (non-marked outcomes indicate quantitative data)

[b]Depending on responses and timing of assessment

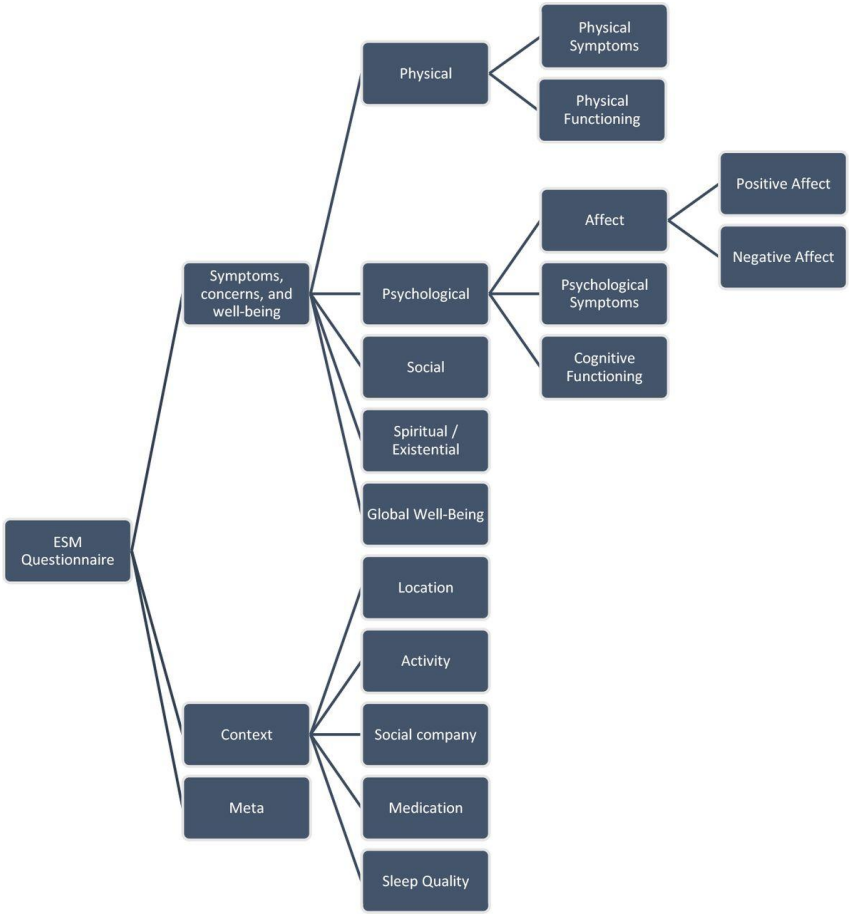
[c]Conducted with healthcare professionals

Digital ESM questionnaire for pilot and observational ESM studies

The digital ESM questionnaire was previously developed and validated in collaboration with people diagnosed with breast and lung cancer and a multidisciplinary group of healthcare professionals.[24] The questionnaire aims to assess symptoms, concerns and well-being and the context in which they occur in people with stage IV breast and stage III or stage IV lung cancer, as well as meta items pertaining to the experience of filling in the

questionnaire (see Figure 2 for an overview of the domains covered by the questionnaire and online supplemental material 1 for the full ESM questionnaire). The items included in the questionnaire were found relevant, appropriate and important by people with stage IV breast and stage III or stage IV lung cancer. More details of the questionnaire development are reported elsewhere.[24] The questionnaire contains a core item list which will be presented to all participants and a supplemental item list from which participants can select items that are relevant to them specifically. Moreover, the first and last assessment of the day are, respectively, assessed using morning and evening versions of the questionnaire. The core morning questionnaire contains 30–34 items (including items on sleep quality), the core momentary questionnaire 29–33 items, and the core evening questionnaire 34–39 items (including items that reflect on experiences across the whole day). The exact questionnaire length depends on the responses on previous items (i.e., conditional items). Response options differ per item and are given as '0–100' slider scales, yes-no and single-choice and multiple-choice questions. The ESM questionnaire will be administered using researcher-provided Motorola e20 devices through the m-Path app.[25,45] M-Path is an easy-to-use online platform that provides a 'flexible framework for implementing smartphone-based EMA and intervention in both research and clinical practice'.[45]

Figure 2. Overview of domains and subdomains covered by our ESM questionnaire. ESM, experience sampling method.



Baseline questionnaire for usability interviews

The 16-item baseline questionnaire of the usability interviews assesses sociodemographic characteristics (including patients' age, social network, work status, education level and religious beliefs), treatment trajectory, cognitive functioning and smartphone use (online supplemental material 2). Cognitive functioning will be briefly assessed through the validated European Organisation for Research and Treatment of Cancer Quality of Life Questionnaire Core 30 (EORTC QLQ-C30) subscale,[32] whereas questions on smartphone use will be based on items from previous studies on this topic[33,34] (e.g., 'How confident do you feel using a smartphone?', using a 5-point Likert scale).

Adapted System Usability Scale for usability interviews

An adapted 17-item version of the System Usability Scale[35] (SUS) will be administered during the usability interviews (online supplemental material 3). The SUS is a widely used reliable scale to efficiently collect users' ratings of a product's usability.[35,46] We changed the wording of the original SUS to pertain to the usability of the 'digital questionnaire' and 'smartphone'. Moreover, we added items related to the instructions, response options, app layout, questionnaire length and the frequency of assessments to better inform us which aspects of the methodology could be optimised (e.g., 'I thought the response options of the digital questionnaire were clear.'). The adapted SUS uses a 5-point Likert scale.

Baseline questionnaire for pilot and observational ESM study

The pilot and observational ESM studies will employ an extended version of the baseline questionnaire for the usability interviews (see 'Adapted System Usability Scale for usability interviews' section), containing 71 items, of which 12 will be completed by the interviewer and other items will be completed by the patient (online supplemental material 4). In addition to the items of the baseline questionnaire, this questionnaire contains items on the individual's socioeconomic status, attitude towards participation in scientific studies, levels of anxiety and depression (Hospital Anxiety and Depression Scale,[36] 14 items), activities of daily living (shortened version of Barthel-Index,[37] 5 items) and instrumental activities of daily living (Lawton IADL,[38] 7 items) and coping style (Brief-COPE,[39] 28 items).

Follow-up questionnaire for pilot and observational ESM study

The pilot and observational studies will use a 59-item follow-up questionnaire battery containing the EORTC QLQ-C30 (30 items) to measure quality of life,[32] the Amnestic Comparative Self-Assessment (7 items) to measure subjective well-being,[40] a

questionnaire to assess the experience of taking part in the study as an indicator of acceptability (19 items, including the following concepts of the Theoretical Framework of Acceptability: affective attitude, burden, opportunity cost, perceived effectiveness, self-efficacy and ethicality[47]) and careless responding (i.e., not paying sufficient attention while responding; 3 items; online supplemental materials 5 and 6). The latter questionnaire was largely based on previous ESM studies in other disciplines.[41–43] The pilot study will include a 17-item adapted version of the SUS similar to the one for the usability interviews, pertaining to the usability of the ESM questionnaire and the study procedure.

Clinical utility interviews for observational ESM study

The interview guides to assess the clinical utility of ESM in oncology among healthcare professionals include 28 questions on previous experiences with monitoring tools and computer technology, reflections on visualisations of patients' responses to the ESM assessments, and reflections on the purpose of ESM for different stakeholders within oncology (online supplemental material 7). The interview guides are based on a survey study that assessed the perspectives of practitioners and researchers on the utility of ESM in mental healthcare.[44]

Study procedures

Eligible participants will be referred by research assistants/data collectors and medical staff at the medical oncology, radiotherapy or pneumology departments of the participating hospitals. If the patient agrees to be contacted by a researcher or contacts the researcher, the researcher will provide them with all study details at the patient's next hospital visit or over the phone. If the patient agrees to participate, the researcher will schedule the interview or baseline session at the patient's preferred place and time. If preferred by the patient, a close person can be present during the interview. To participate, patients identified through peer support groups will need to initiate contact with the researcher themselves. Written informed consent will be collected before or at the start of the initial research session.

Step 1: pretesting (usability interviews)

At the start of the session, the patient will complete a baseline questionnaire with the researcher reading the questions out loud (interview guide in online supplemental material 8). Next, the patient will be provided with a smartphone device and briefly instructed on how to open and use the m-Path application.[25] The patient will be asked to fill in a digital ESM questionnaire on the provided smartphone device, while thinking out loud. The patient

will be asked whether something is not clear if the researcher observes difficulties with responding.

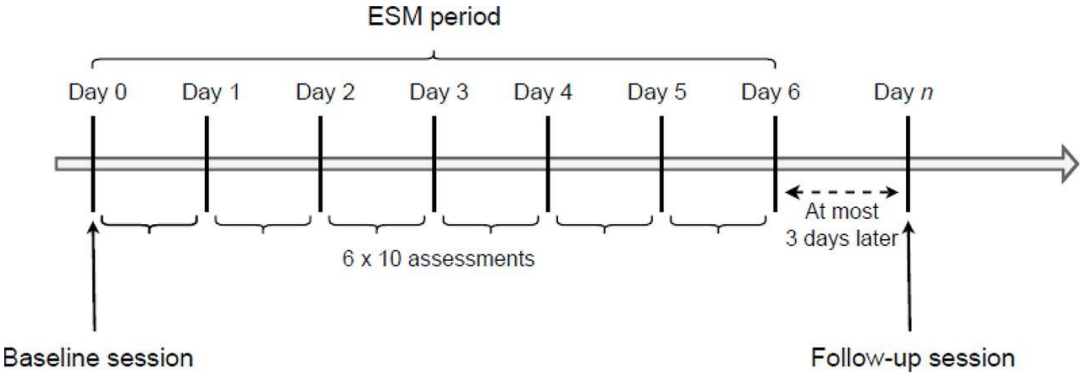
After completing the digital questionnaire, we will conduct a brief semistructured interview concerning the usability of the digital questionnaire. Where possible, we will ask the patient to provide more information on why a particular quality of the digital ESM questionnaire or the smartphone device is deemed more difficult to work with.

Lastly, the patient will complete the same digital ESM questionnaire from the beginning of the session again, but this time without thinking out loud. The last assessment of the digital ESM questionnaire will provide estimates on how much time it takes to fill in the questionnaire. The entire session is expected to take between 30 and 40 min.

Step 1: pretesting (pilot ESM study)

The pilot ESM study procedure contains a baseline session, a 6-day ESM period and a follow-up session (Figure 3).

Figure 3 . Overview of ESM study procedure.



Baseline session. At baseline, the researcher or research assistant will ask the patient to complete the baseline questionnaire. The researcher will train the patient in using the digital ESM questionnaire on the provided smartphone device and afterwards ask to unlock the phone, open the digital ESM questionnaire, and fill in the questionnaire, to check if the training was sufficient. Afterwards, the researcher will ask if the patient wants to choose additional items from the supplementary ESM list, with a focus on constructs that are meaningful to them and have potential impact on their daily life, to expand and personalise the core questionnaire for the ESM period. If present, the patient's close person may help in looking for supplementary items. The researcher will provide an informational page with instructions to take home and will schedule a follow-up session with the patient, preferably

1 week after the baseline session. The entire baseline session is expected to take 30–40 min.

ESM period. Starting on the same day directly after the baseline session, participants will receive up to ten prompts for ESM assessments, depending on the time of day when the baseline session was completed (Figure 3). A total of 60 ESM assessments will be scheduled over 6 days, meaning 10 prompts per day. Such an ESM schedule was shown to adequately balance the resolution required to assess variability of target constructs and assessment burden for vulnerable participants.[30,48] Participants will be prompted to complete the ESM questionnaire at semirandom times through a sound alert ('beep'), scheduled to start at least 1 hour after waking and at most 1 hour before going to bed (determined individually, before the ESM period). A minimum time of 30 min will be scheduled between consecutive assessments. After the first full day of assessments, the researcher or research assistant will phone the patient to check whether they have any questions or are experiencing technical difficulties. Throughout the 6-day ESM period, the researchers will be available by telephone and email to help patients with possible problems.

Follow-up session. In the follow-up session, postmeasurements will be conducted. The follow-up questionnaire will preferably be conducted within 1 day or at most 3 days after ESM period completion. After completing the questionnaire, the researcher will invite the patient to participate in the semistructured interview following a questionnaire to evaluate the patient's experiences of using the ESM tool during the study period. At the end of the session, the researcher will provide the patient with a paper version of a visual summary of the patient's ESM data and will send a digital PDF version via email. The audio of this session will be recorded with the patient's consent. The follow-up session is estimated to take 50 min.

Step 2: observational ESM study

ESM study. The data collection procedure for the observational ESM study will be analogous to the pilot ESM study but with a shortened follow-up questionnaire. Lessons learnt during the pilot study may result in changes to participant instructions and other aspects of the methods.

In the baseline session of the observational ESM study, patients will be given the option to have their responses to the ESM assessments shared with healthcare professionals to explore the clinical utility of ESM assessment. As patients willing to share their data run the risk of getting recognised by the healthcare professionals, we will ask those patients to provide additional informed consent. If a patient declines to share their data with

healthcare professionals, the data will not be used in the testing of clinical utility, but will still be included in the ESM study where pseudonymisation is ensured.

***Clinical utility interviews with treating oncologists and oncopsychologists*.** Treating oncologists and oncopsychologists of a purposive sample of consenting participants of the observational ESM study will be contacted to schedule a semistructured interview at a preferred location. Before the start of the interview, the researcher will ask the healthcare professional to provide written informed consent. The healthcare professional will receive the visual ESM summary of their patient and will be given time to visually explore it. If no patients agreed to have their data shared, all clinical utility interviews will be conducted using hypothetical data generated by the researchers to mimic real patient responses. The interview will be recorded with the participant's consent. The interview session is estimated to take 60 min.

Clinical utility interviews with nursing staff. Nursing staff members will be recruited through the research teams' professional networks. The interviews will follow a similar procedure as the oncologist and psychologists interviews, but patient names will not be disclosed to the staff being interviewed. The audio of this session will be recorded with the participant's consent. The interview session is estimated to take 60 min.

Outcomes

Step 1: pretesting

During pretesting, outcomes for the usability interviews will include the readability, comprehensibility, ease-of-use of the ESM questionnaire in the smartphone application, reasons for difficulties encountered, time required to complete the ESM questionnaire, expected burden of multiple daily assessments for 6 days and ways to lessen this burden, and patient characteristics that may affect questionnaire completion time. These outcomes will inform optimisation of the ESM methodology and procedure for the pilot and observational ESM study.

Outcomes for the pilot ESM study will include the response-related characteristics of the ESM period indicative of its feasibility (i.e., compliance rates, missing data patterns), patient experiences with the study method and procedure as an indication of acceptability, reasons for difficulties encountered, time required to complete the questionnaire, patient demographics, smartphone use, functional and cognitive state, anxiety and depression levels, activities of daily living, and coping style. These outcomes will identify factors to optimise the ESM methodology and procedure for the observational ESM study.

Step 2: observational ESM study

In the observational ESM study, outcomes will assess the relationship between ESM and retrospective patient-reported outcome data, levels of within-person and between-person variation in daily experiences, within-person and between-person temporal relationships between daily experiences (including contexts), response-related characteristics of the ESM period indicative of its feasibility (i.e., compliance rates, missing data patterns), patient experiences with the study method and procedure as an indication of acceptability, reasons for difficulties encountered, the moderating role of baseline constructs (e.g., IADL) on temporal relationships, patterns of missing data and their relationship with baseline patient characteristics, and visual summaries of individual patient ESM data.

The visual summaries of ESM data will be used for the outcomes of the clinical utility interviews, which will explore the perceptions of healthcare professionals on the concrete and potential clinical value of using ESM in oncology clinical practice and research.

Patient and public involvement

We reported public and patient involvement guided by the Guidance for Reporting Involvement of Patients and the Public 2 - Short Form (GRIPP2-SF) reporting checklist.[49] To improve the relevance of our study for the target population and clinical practice, we systematically developed and validated our ESM questionnaire in collaboration with 34 patients and 8 healthcare professionals through semistructured interviews.[24] Moreover, patient representatives at Ghent University Hospital discussed and provided feedback on the ESM questionnaire and procedure, which led to minor changes in wording of items and instructions. Overall, the patient involvement shaped our ESM questionnaire, and we experienced patients as engaged and open to share their views.

In this study, pretesting of our ESM questionnaire and procedure will provide opportunities for at least 20 patients to give feedback on their experiences with the study to ensure a user-friendly ESM method for participants in the observational ESM study and future studies.

Data analyses

We will use descriptive statistics to show the sample characteristics gathered at baseline and follow-up. Continuous variables will be reported through means and SD, while categorical variables will be reported through frequencies and percentages.

We will use R for all data analyses and visualisations, with the lme4 package for multilevel modelling. We will use NVivo V.20 software to transcribe all audiorecordings and to conduct content analyses. All content analyses will follow conventional content analysis using inductive category development as described by Hsieh and Shannon,[50] which chronologically includes familiarisation with data, coding of the text, labelling the codes, creating categories (with possible overarching categories) and reporting.

Step 1: pretesting (usability interviews)

We will summarise quantitative data on readability, comprehension, ease-of-use, expected burden gathered with the usability questionnaire using descriptive statistics (ie, means and SD).

Questionnaire completion times will be analysed descriptively. A median time above 3 min will indicate that a questionnaire is too long.

We will conduct content analysis on the interview transcripts to explore aspects that influence the usability of the ESM questionnaire,[50] such as difficulties or conveniences in the user experience or comprehension of the questionnaire and application.

Step 1: pretesting (pilot ESM study)

ESM data. We will use descriptive analyses to assess compliance (i.e., number of completed assessments divided by the total number of scheduled assessments), attrition, momentary burden and questionnaire completion times. Multilevel linear regression models will be used to analyse compliance as a function of patient characteristics, time and levels of outcome variables and to explore temporal variation in responses on a within-person and between-person level.

Follow-up data. We will use descriptive analyses to summarise follow-up questionnaire data. Content analysis will be used to explore difficulties with the ESM questionnaire or procedure.[50]

Step 2: observational ESM study

In addition to the analyses described for the pilot ESM study, we will employ vector autoregressive multilevel modelling to explore within-person and between-person temporal relationships among patient experiences, context and context appraisals.[51,52] Furthermore, we will examine the moderating role of baseline measures (e.g., IADL, social network) on these temporal relationships.

To further analyse the data, we will calculate mean scores for each construct measured with a slider scale across 6 days for each participant. Pearson correlations will be used to investigate the relationship between the mean scores and similar constructs measured retrospectively in follow-up sessions.

We will conduct content analyses of the qualitative data obtained from the clinical utility interviews to identify themes that highlight the concrete and potential clinical value of ESM in oncology clinical practice and research.[50]

Data management plan

JG will transcribe all audiorecordings and destroy them immediately afterwards. We will assign identification codes to participants, ensuring pseudonymity and we will restrict access to the key file to a select few individuals (JG and LP). We will enter non-ESM questionnaire responses into Qualtrics and download the datasets. We will download the ESM data from secure m-Path servers. Only approved team members will have access to the databases. We will securely store data on the central network drive of the Vrije Universiteit Brussel SharePoint servers for 25 years after study completion. Following the publication of the main results of the observational ESM study, the respective data will be made available for non-commercial research purposes on a reasonable request made to the researchers.

Safety protocol

Previous ESM studies in similar populations suggest acceptability of the procedure,[17,18,53,54] and we, therefore, anticipate no serious adverse events. What may occur is mild psychological discomfort or distress due to questions about one's health and well-being and frequent assessments. Before giving informed consent, participants will be fully informed of potential risks and sources of psychological distress, such as reactivity to negative questions or irritation from repeated assessments. They may refuse to answer any question or ESM prompt. In case of adverse events, participants can contact the research team, several of whom have master's degrees in psychology. The researcher will provide contact information for psychological support at the participant's treating hospital, if appropriate.

Limitations

Due to the nature of the methodology, possible study limitations are to be expected. First, the ESM studies will only collect data over a limited time, and as such, it may not capture the full range of experiences and fluctuations that occur within individuals over a longer period of time. Moreover, the specific inclusion of patients with advanced breast or lung

cancer limits the generalisability of findings towards people with other forms of cancer at different disease stages.

Second, selection bias may be apparent due to the self-selection of, for instance, patients who are more experienced and confident in using digital technology or those interested in research. As this may limit the generalisability of the results to the broader population of people with advanced breast or lung cancer, we will include experience with smartphone technology in the baseline questionnaire to describe this for our sample and check for possible associations with missing data and study experience. Moreover, to lower the participation threshold for people with less experience using smartphones, interested patients will be reassured that the system will be easy to use and will include clear instructions. Additionally, we will purposively include an equal number of people aged above and below 70. We will analyse reasons for non-participation to screen for possible selection bias.

Third, in addition to potentially causing selection bias, lower levels of digital literacy may introduce negative study experiences for patients or limit the study's feasibility, for instance, due to difficulties in working with the smartphone device or ESM application. To mitigate these risks, our study implements comprehensive training and clear instructions, maintains communication between researchers and participants regarding technical difficulties during the study, and registers participants' levels of smartphone experience.

Fourth, the ESM study requires patients to carry a researcher-provided smartphone with them. This could lead to people forgetting the phone or forgetting to charge the battery, leading to missing data. Therefore, participants will be reminded to charge the phone and always keep it with them. To ensure data completeness, the researcher (JG) will conduct a follow-up check after 1 day to confirm a smooth study procedure and experience.

Ethics and dissemination

The current protocol has received ethical approval by the ethics committees of the University Hospitals Brussels (BUN: 1432023000043) and Ghent (ONZ-2023-0136). The research will be conducted in accordance with the Declaration of Helsinki and applicable Belgian and European legislation.

We will pseudonymise all data, except visual ESM summaries presented to oncologists and oncopsychologists. We will not publish data that could lead to the identification of participants.

Written informed consent by participants will be required for participation in this study. We will make participants aware that participation is voluntary and that they may withdraw from the study at any time, without negative consequence for the study or their relationship with the research or treating team. We will provide no monetary incentives for participation in this study.

We will make available and publish all study documents and questionnaires as online supplemental data. Results from this study will be used to write several manuscripts to submit to open access peer-review journals and to present at national and international conferences and other forums for the dissemination of knowledge.

Ethics statements

Patient consent for publication

Not applicable.

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Contributors

Conception and design of the work: LP, LVdB and JG. Ethics committee application: JG, LP, KDN, EN, GC, MDR and LVdB. Drafting of the article: JG, LP, KDN and LVdB. Critical revision of the manuscript: JG, LP, KDN, EN, GC, MDR and LVdB. All authors read and approved the final manuscript.

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Competing interests

None declared.

Supplementary Materials

Supplementary Material 1: Digital ESM questionnaire for pilot and observational ESM studies
Supplementary Material 2: Baseline questionnaire for usability interviews (Dutch)
Supplementary Material 3: Adapted System Usability Scale for usability interviews (Dutch)
Supplementary Material 4: Baseline questionnaire for pilot and observational ESM study (Dutch)
Supplementary Material 5: Follow-up questionnaire for pilot ESM study (Dutch)
Supplementary Material 6: Follow-up questionnaire for observational ESM study (Dutch)
Supplementary Material 7: Clinical utility interview guides for observational ESM study (Dutch)
Supplementary Material 8: Interview guide for usability interviews (Dutch)

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CHAPTER 5

The potential of experience sampling methods in palliative care.

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Abstract

Background

Experience sampling methods typically involve multiple self-report assessments per day over consecutive days. Unlike traditional patient-reported outcome measures or interviews, such methods offer the possibility to capture the temporal fluctuations of experiences in daily environments, making them valuable for studying the daily lives of people with advanced illness. Yet, their use in palliative care research is limited.

Aims

To introduce experience sampling methods to the field of palliative care as a valuable tool for studying the everyday experiences of people with advanced illness, and to present the findings of an experience sampling methods pilot study with people with advanced breast or advanced lung cancer.

Evidence used to support the information presented

We draw on published health research using experience sampling methods. We present a newly developed experience sampling methods questionnaire (ESM-AC) and report pilot study findings on the feasibility and acceptability of experience sampling methods among people with advanced breast or lung cancer.

Key learning points

Experience sampling methods hold potential to uncover the dynamics of everyday experiences of people with advanced illness. The methods offer considerable flexibility and options to answer a variety of research questions, but consideration is required regarding sampling protocols and participant burden. We showed appropriate feasibility and acceptable participant burden of the methods among people with advanced breast or advanced lung cancer.

Introduction

Experience sampling methods, also known as ecological momentary assessments, are intensive longitudinal self-report methods that typically involve multiple assessments per day, for several consecutive days, which are usually completed on a smartphone device.[1] Experience sampling methods are well-established in the fields of mental health and pain research,[2–4] and, due to their potential to gain insights into the everyday lives of patients, they are increasingly gaining attention in other research fields. However, in palliative care research, the potential of these methods remains largely unexplored.

In this paper, we aim to: (1) introduce experience sampling methods to the field of palliative care as a novel and potentially valuable tool for studying the everyday experiences of people with advanced illness; and (2) present findings on the feasibility and acceptability of a pilot experience sampling methods study for which we developed and validated a questionnaire (i.e., the ESM-AC questionnaire) to uncover the symptoms, concerns, and well-being of people living with advanced breast or advanced lung cancer.[5] We discuss the implications of our findings and make recommendations for the use of experience sampling methods in palliative care research.

Experience Sampling Methods in the Field of Palliative Care

Background of Experience Sampling Methods

Patient-reported outcome measures and interviews are valuable tools for assessing patient experiences and quality of life in palliative care practice and research.[6–8] These retrospective tools typically require patients to recall and aggregate the intensity, frequency and/or associated burden of their symptoms or other experiences over days or weeks (e.g., "During the past week, were you tired?").[6,8] In contrast, experience sampling methods use repeated assessments (often up to 10 times per day for a week) that measure experiences in the moment (e.g., "At this moment, I feel tired."), or over a brief period (e.g., "Since the last prompt, I have been affected by poor mobility", or "Today, I felt supported by others"). These experiences can include symptoms, emotions, thoughts, and behaviours, and they are often supplemented with questions about the contexts in which they occur (e.g., social company or activities at the moment of the questionnaire prompt). Experience sampling methods allow the temporally fine-grained investigation into how people's experiences occur, fluctuate, and correlate with each other within and across days, which helps identify what influences variation in experiences. This information can lead to the identification or development of novel personalized targets for interventions.[2] For example, experience sampling methods can provide fine-grained insights into how

symptoms, such as fatigue, fluctuate throughout the day and how these fluctuations relate to the person's other experiences at the same or previous measurement moment(s).[9] Importantly, it is assumed that, by measuring experiences in real-time, experience sampling methods minimize the effects of memory biases present in traditional retrospective measures[10] and improve the ecological validity of findings as people are assessed in their natural environments.[2]

Experience sampling methods offer flexibility, as readily available digital platforms give researchers and clinicians the opportunity to tailor study designs to the question at hand.[1] For example, researchers might choose to prompt measurements at random intervals during the day (i.e., random signal-contingent sampling), or they can instruct patients to complete assessments when certain events or behaviours occur (i.e., event-contingent sampling), such as breakthrough pain episodes.[11,12] Additionally, important trade-offs among the number of items, assessments, and study duration necessitate careful design and testing of the questionnaires. Equally important is the consideration of the extent to which the method suits the individuals under study and their daily environments (such as whether smartphones can be used).[1,13]

Current Use and Potential of Experience Sampling Methods in Palliative Care

To date, the use of experience sampling methods among palliative care populations remains limited. Recent reviews[12,14] have identified 42 studies with people with cancer, using experience sampling methods to study a variety of topics, such as associations between daily hope and same- and next-day role functioning[15], and associations between real-time fatigue and physical activity[16]. However, most studies prompted participants only once per day; and studies with people with Stage IV (metastatic) cancer were scarce, with only 3 studies using multiple assessments per day among this particular group.[12,17–19]

Applications of experience sampling methods in the fields of mental health and pain research[3,4] might translate well into the context of palliative care. If proven feasible among populations of people with advanced illness, the methods could be used to address important research questions regarding patients' well-being and symptoms and they could potentially inform person-centred clinical interventions. Examples of research questions that could be addressed using experience sampling methods are presented in Table 1.

Table 1. Types and examples of research questions that can be answered using experience sampling methods in palliative care research.

Types of research questions	Examples of research questions
Related to the behavior of one time-varying variable	How do people with serious illness feel, think, or behave on average in their daily lives?
	How do symptoms or emotional distress of people with serious illness fluctuate over time (e.g., across one day or a week)?
	To what extent is a negative mood state or a physical symptom experienced by people with serious illness predictive for itself on a later timepoint?
Related to the behavior of multiple time-varying variables	How do variations in social interactions of people with serious illness relate to variations in experienced symptom burden and mood states?
	How do symptoms, concerns, and mood states of people with serious illness interrelate as nodes in a network?
	To what extent does a negative mood state predict physical symptoms on a later timepoint?
Related to person-level characteristics	To what extent do the patterns of symptoms and emotions experienced by people with serious illness differ between persons?
	To what extent do personal characteristics, such as sociodemographic, clinical, personality, or habitual coping strategies, impact variations in symptoms and mood states (i.e., what are protective and risk factors)?
Involving non-natural variation	How do people with serious illness' symptoms, feelings, thoughts, and/or behaviors fluctuate around periods of receiving bad news?
	How does a certain intervention or treatment affect people with serious illness' symptoms, feelings, thoughts, and behavior (e.g., treatment-toxicity related to chemotherapy or effectiveness of psychotropic medication in reducing anxiety)?
	To what extent do the temporal patterns of experienced physical symptoms of people with serious illness predict improved outcomes of a treatment?

Note. The types of research questions are inspired by the Open Handbook of Experience Sampling Methods (Myin-Germeys & Kuppens, 2021).

Experience sampling methods could also be implemented for use in clinical settings.[3,20] One example is the use of 'ecological momentary interventions', whereby patients can receive real-time feedback based on their responses (i.e., just-in-time interventions) or can review their responses together with a healthcare professional to tailor their treatment to their specific needs (i.e., blended care intervention).[1]

Challenges When Using Experience Sampling Methods

While the use of experience sampling methods can enrich our understanding of (end-of-life) experiences, these methods come with challenges.[21,22] Selection bias poses significant risks, potentially skewing samples towards over- or under-representation of certain groups: e.g., conscientious individuals who are more willing to participate in research, or those who own or are proficient in smartphone technology.[22] Moreover, some applications require network connectivity, which, together with selective inclusion of the latter groups could widen the digital divide in mHealth research.[23] Providing participants with devices or pen-and-paper alternatives can help mitigate this.[1] Completing the assessments also requires motivation and could also be difficult for people with concentration problems (for example, due to deterioration because of disease).[22] Therefore, researchers should be cautious about generalizing their findings towards wider populations. Moreover, participants' choices in responding to signals or carrying the device may result in under-representation of certain situations.

Measurement reactivity, another challenge of the method, relates to the fact that repeated assessments of experience sampling methods could cause the phenomenon under study to change – e.g., repeated assessments of pain could cause participants to report more pain due to their increasing awareness of pain.[2,22,24] This problem is currently under-studied in experience sampling research. Additionally, the complexity of planning, implementing, and analysing the rich longitudinal data collected through experience sampling methods necessitates adherence to established guidelines and the use of advanced statistical techniques.[1]

Intensive assessment schedules may burden patients already vulnerable due to high symptom burden. In research outside of palliative care, the use of intensive assessment schedules has been proven feasible and acceptable among vulnerable populations, such as people with chronic pain or people with psychopathological disorders like schizophrenia or major depressive disorder.[4,25,26] However, explicitly testing the feasibility and acceptability of these assessment schedules among palliative care populations is a crucial first step in the adoption of experience sampling methods in the field of palliative care. For people with advanced cancer, these methods appear to be feasible, but more testing is required. In

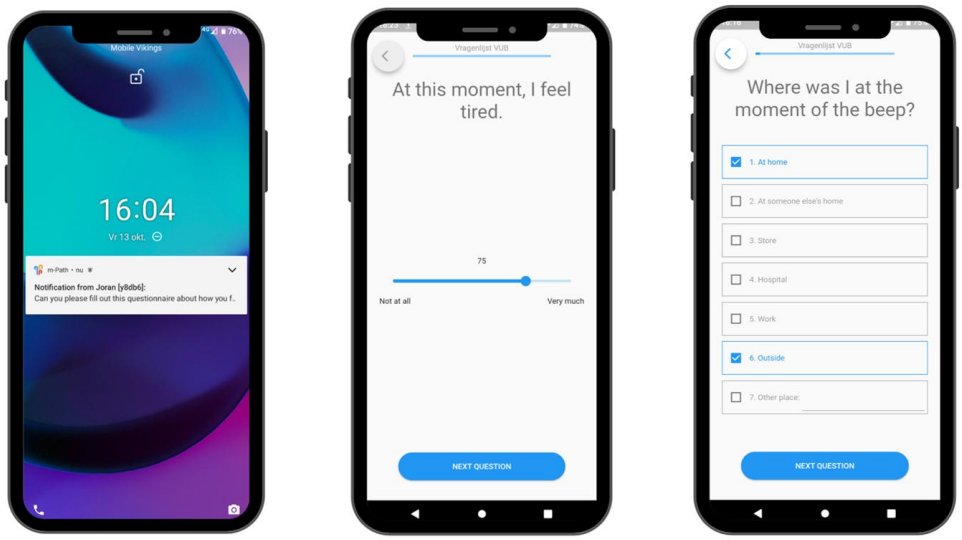
particular, the testing of more intensive assessment schedules is required, as the number of assessments per day in studies using experience sampling methods among people with cancer is generally low and therefore provides less fine-grained insights into symptoms, concerns, and well-being as experienced during the day.[12] For these reasons, we present the findings of our experience sampling methods pilot study as a first step in testing the methods' feasibility.[27]

Experience Sampling Methods Pilot Study

Background: The Experience Sampling Methods in Advanced Cancer Questionnaire (ESM-AC)

To better understand the symptoms, concerns, well-being, and daily contexts of people with advanced breast or advanced lung cancer in their everyday lives, we developed and validated an 'experience sampling methods in advanced cancer questionnaire', which we named the ESM-AC questionnaire.[5] We followed the EORTC and COSMIN guidelines for patient-reported outcome measure development,[28,29] as no specific guidelines for experience sampling methods questionnaires were available. Moreover, we were among the first in experience sampling research – across health disciplines – to explicitly assess the content validity of items to be used in an experience sampling methods questionnaire.[5,12,14,30] Content validity is a crucial indicator of whether the content of an instrument is an adequate reflection of the construct being measured.[28,30] The questionnaire covers physical (including physical symptoms and functioning), psychological (including positive and negative affect, psychological symptoms, and cognitive complaints), social, spiritual-existential, and global well-being domains, as well as concurrent contexts (including the patient's activity, social company and location at the moment of the assessment), and people's experiences while completing the questionnaire (e.g., finding the questionnaire burdensome). We developed and content-validated the questionnaire with 43 people with advanced breast or advanced lung cancer, and 8 healthcare professionals. The resulting questionnaire consists of 31 items and is optimized to be conducted using *m-Path*, a smartphone application specifically designed for experience sampling methods (Figure 1; see Supplementary Material 1 for the questionnaire items).[5,31] Our next step was to conduct a pilot study with people with advanced cancer to assess the feasibility and acceptability of the novel ESM-AC questionnaire administered in an intensive experience sampling methods protocol.

Figure 1. Screenshots of our digital experience sampling methods questionnaire in the m-Path application (translated from Dutch to English).



Notes. Left: receiving a notification; Middle: Example of slider response scale; Right: Example of multiple-choice response scale

Methods

Aims. We aimed to: (1) gain insights into the feasibility and acceptability of conducting an experience sampling study with people with advanced breast cancer or advanced lung cancer using the ESM-AC questionnaire; (2) provide insights into fluctuations in experiences and visually compare these fluctuations across participants with differing and identical retrospective questionnaire scores; and (3) optimize the study methods before conducting a larger experience sampling methods study.

Design. We conducted a pilot observational experience sampling methods study.

Participants and Setting. We included 12 people with either Stage IV breast or Stage III or IV lung cancer from 2 university hospitals in Belgium (in the Flanders and Brussels regions), between June 2023 and August 2023, purposively sampled to create 4 equally-sized groups based on age below or above 70 years and diagnosis of breast or lung cancer. More details are reported in the published study protocol.[27]

Materials and Procedures. Each of the participants received a Motorola E20 smartphone with the *m-Path* application for experience sampling methods research installed.[31] Using a sound signal that lasted approximately 30 seconds, participants were prompted 10 times per day over 6 consecutive days to complete the ESM-AC questionnaire at random times within equally-spaced time blocks, for instance, on a random time between 16h30 and 17h30.[27] A period of six days was chosen to adequately balance the resolution required to

assess variability and assessment burden for participants.[32,33] Participants could start the questionnaire up to 5 minutes after each prompt. At the baseline session, participants received instructions and training for using the digital questionnaire and they completed a baseline questionnaire on socio-demographic information and smartphone familiarity. Within 2 days after starting the experience sampling methods period, the researcher called the participant to ensure proper understanding and use of the digital questionnaire. At most 3 days after the 6-day period, the researcher collected the smartphone, administered a follow-up questionnaire (in the form of a semi-structured interview) regarding the participant's experiences with the method, following a visible response scale (1 = "Don't agree at all" to 5 = "Completely agree"). Patients also completed the EORTC-QLQ-C30 quality of life questionnaire, measuring global health status, patient functioning, and symptoms.[34] Across the study, the researcher noted patient feedback and challenges. More procedural details are reported in the study protocol.[27]

Analyses. We calculated descriptive statistics of sample characteristics, study metrics (compliance, participation, and attrition rates), and follow-up questionnaire responses. We conducted inductive content analyses on the feedback provided during the follow-up questionnaire and on the difficulties that the patients experienced.[35] We created time series graphs for all continuous scale experience sampling methods items, ordered based on corresponding retrospective EORTC-QLQ-C30 responses where available.

Results

Twelve out of 23 approached patients participated (52%). Reasons patients indicated for non-participation were: having no time (n=3), expecting difficulties with smartphone use (n=2), no interest in research (n=2), a close person perceiving the study as too complex for the patient (n=1), and preferring to participate in a later study stage (n=1). One patient provided no reason, and another did not respond to the researcher.

Characteristics of the included sample are provided in Table 2. All patients reported owning a smartphone, with all but one expressing neutral or positive confidence in using it. One of the 12 participants dropped out after 3 days of the data collection period due to irritation caused by the questionnaire interrupting his rest and always having repetitive content; and another participant did not complete the follow-up questionnaire due to hospitalization.

Table 2. Characteristics of experience sampling methods pilot study sample.

Characteristic	Descriptive statistic (N=12)
Age (years)	
M (*SD*)	66.6 (8.2)
Range	50-76
Gender (n female)	8
Educational level (n)	
Primary	1
Secondary	2
Tertiary	9
Employment status (n)	
Professionally active	1
Not professionally active	11
Cancer diagnosis (n)	
Stage III or IV lung cancer	6
Stage IV breast cancer	6
Treatment(s) received, as reported by patient[a] (n)	
Chemotherapy	10
Radiotherapy	7
Surgery	5
Anti-hormonal therapy	4
Immunotherapy	6
EORTC QLQ-C30 concentration problems (n)	
Not at All	12
Smartphone ownership in years, *M* (*SD*)	9.9 (5.2)
Daily time spent on smartphone in minutes, *M* (*SD*)	83.7 (66.3)
Confidence using smartphone (1 = "Not at all confident", 5 = "Very confident"), *M* (*SD*)	3.7 (1.0)

Abbreviations. M = mean, *SD* = standard deviation

[a]Multiple answers possible.

On average, participants completed 80% of the scheduled assessments (*SD* = 16), with an average completion time of 3.08 minutes (*SD* = 0.85) per assessment (Table 3). On average, participants deemed the digital questionnaire and smartphone easy to use, the questions and instructions readable, the questionnaire not inconvenient or too long to complete, and the study period not stressful or tiresome (Table 3; more details in

Supplementary Material 2). Participants' ratings were more mixed, i.e., ratings with means more in the middle of the scale and higher variability (standard deviations) for whether they would like to use the questionnaire regularly in their daily lives, whether the questionnaire became boring during the past week, and whether the number of assessments for each day was too high (Table 3).

Table 3. Experience sampling methods pilot study findings on feasibility and acceptability**.**

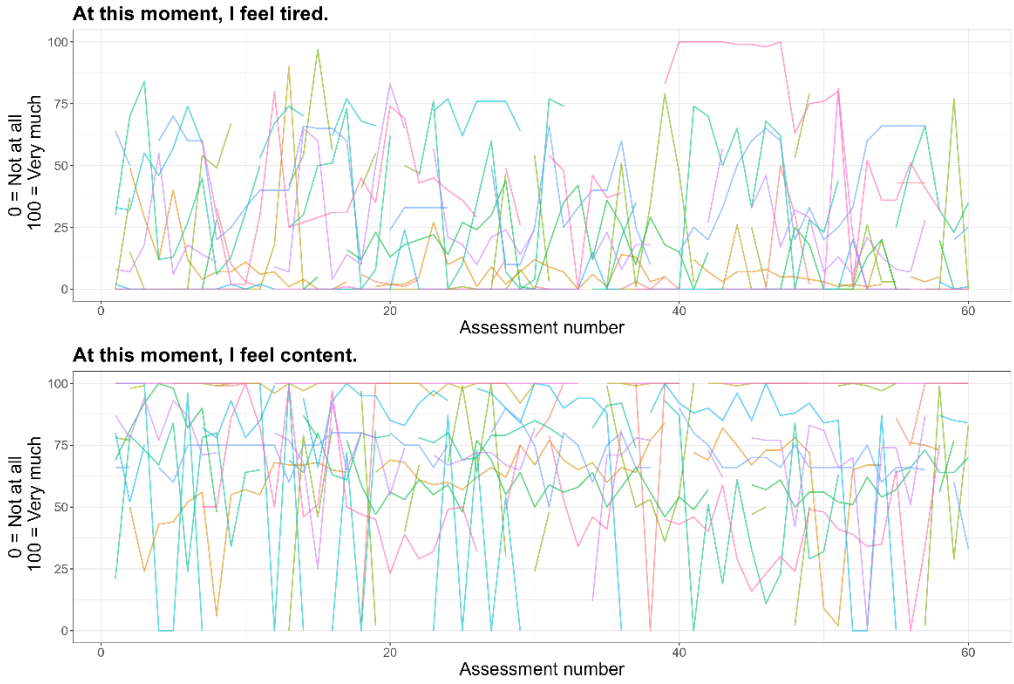
Study findings	**Descriptive statistics**
Feasibility	
Number of approached patients	23
Number of included patients	12
Study drop-outs	
Experience sampling methods period	1
Follow-up questionnaire	1
Mean percentage of completed out of scheduled assessments [M (SD)]	80 (16)
Minutes to complete experience sampling methods questionnaire [M (SD)]	3.1 (0.9)
Acceptability (1 = "Don't agree at all" to 5 = "Completely agree"), *M* (*SD*)	
Easy to use smartphone device	4.82 (0.4)
Easy to use digital questionnaire	4.82 (0.4)
Questions and instructions were readable	4.55, (1.21)
Completing the whole questionnaire was inconvenient	1 (0)
Questionnaire was too long	1.18 (0.4)
Questionnaire was stressful	1.45 (0.93)
Questionnaire was tiresome	1.36 (1.21)
Would like to regularly use questionnaire in daily life	2.45 (1.29)
Questionnaire became boring during study period	2.55 (1.51)
Number of assessments was too much	2.82 (1.66)

Abbreviations. M = mean, *SD* = standard deviation

Visual inspection of the time series data from the experience sampling methods showed great variability of experiences within and between patients. While some patients consistently reported lower levels of symptoms, concerns, or well-being, others reported varying levels throughout the day, with different maximum levels and rates of change

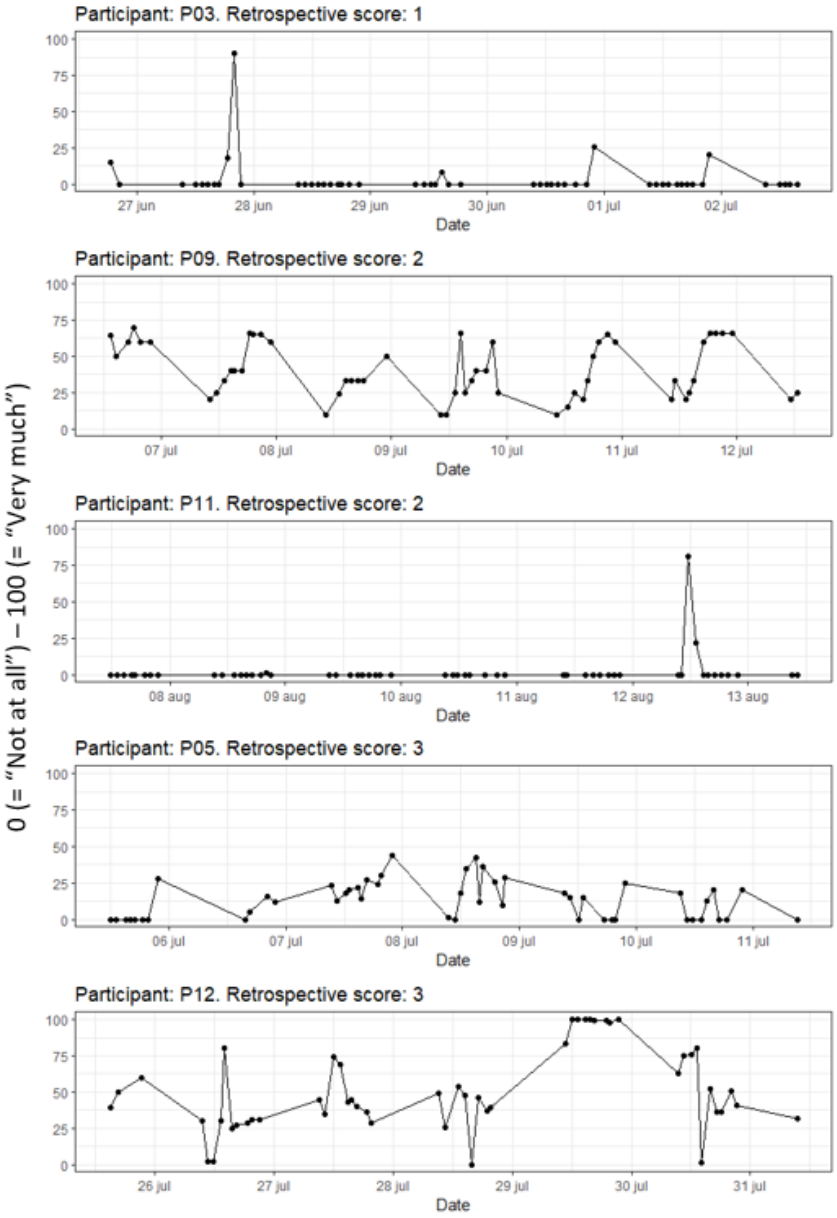
(Figure 2; full list of graphs in Supplementary Material 4). Notably, comparing individuals with similar scores on retrospective questionnaire items revealed distinct patterns of real-time experiences as measured with experience sampling methods. For instance, despite identical retrospective tiredness scores, the visualisations show considerably different real-time tiredness patterns between participants (Figure 3).

Figure 2. Illustrative selection of time series spaghetti plots, with each differently coloured line representating a different participant.



Based on participant feedback and observed difficulties, we made changes to the experience sampling methods questionnaire and procedure, follow-up questionnaire, smartphone settings, and the baseline interview guide and instructions (Supplementary Material 3). Important adaptations included changing the experience sampling methods 'depressed' item wording to 'down', extending the time to open the questionnaire to 10 minutes, and adding training instructions and the follow-up item "I think I have switched up the response scale of the questions" (1 = "Never" to 7 = "Always"). Additionally, the study drop-out highlighted the importance of researcher check-up calls after the first study days to assess distress in addition to checking for technical problems, as well as instructing patients to place the device in another room during rest periods.

Figure 3. Illustrative selection of time series visualizations for the item "At this moment, I feel tired" (ordered by response on the corresponding EORTC-QLQ-C30 item).



Note. Retrospective scores indicate participants' responses on the EORTC-QLQ-C30 item "During the past week, were you tired?". Values correspond to 1 = "Not at all", 2 = "A little", 3 = "Quite a bit", 4 = "A lot".

General Discussion

This paper demonstrates how experience sampling methods, established in other research domains, can be adapted to, and employed in, palliative care research. These methods can be a powerful tool to study the fluctuations and associations of critical patient experiences, through which they can inform future patient-centred interventions. Our pilot study among

people with advanced cancer provides an example of how the close involvement of patients and healthcare professionals can result in a method that is user-friendly and acceptable.[5]

Interpretation of Pilot Study Results

Overall, older and younger participants with different levels of symptom burden completed enough assessments for analysis, with, in general, no burden caused by the experience sampling methods. Only 1 of the 12 participants dropped out of the experience sampling methods period due to irritation and tiredness.

The considerable variability shown in most of the measured experiences highlights the relevance of using experience sampling methods and intensive assessment schemes to map the daily fluctuations of these experiences in everyday life. Moreover, comparing real-time patterns between people with similar EORTC-QLQ-C30 scores shows the rich variability of experiences that experience sampling methods can uncover within and across days, beyond traditional retrospective assessments. These findings further strengthen recent perspectives in oncology and other fields that patient's symptoms, concerns, and well-being, such as pain, fatigue, or emotional states, are complex dynamic experiences.[36–38]

Strengths and Limitations of the Pilot Study

The study's strengths include the use of pre-tested user-friendly smartphone technology that was developed in close collaboration with advanced cancer patients and healthcare professionals,[5] and the equal inclusion of patients below and above the age of 70 to ensure inclusion of the latter, often-under-represented, group in cancer studies.

The study's limitations include a possible selection bias, as some patients declined participation due to having limited smartphone experience, while all included participants owned smartphones and most of them felt relatively confident using them. The relatively high functional status of our sample (i.e., ECOG scores between 0 and 2) may also limit the generalizability of the findings, particularly to patients with advanced cancer who are facing more pronounced functional limitations.

Implications for Future Research

It is our hope that the overview of the methods' potential and the findings of our pilot study will encourage researchers to further explore the relevance of these methods in palliative care. The questionnaire that we developed for people with advanced cancer can

serve as a starting point for researchers interested in using experience sampling methods in different populations, given its likely relevance to other advanced illness populations. But due to the novelty of these methods in our field, and the vulnerability of the target populations, it is essential to assess the methods' feasibility and potential burden beforehand. As our study showed through its resulting changes made to the methods, the methodological evaluation of experience sampling methods can require iterative testing to optimize the methods.

To improve the transparency and comparability of study methods and findings, we recommend following the CREMAS checklist for reporting ecological momentary assessment studies,[39] facilitating standardized reporting and identifying optimal design choices. Moreover, drawing from our pilot study findings, we suggest implementing check-up calls early in the experience sampling methods period to detect and address burden and distress related to the study. Participants should be encouraged to place the smartphone device in another room when resting, to avoid interruptions. Additionally, with recent advances of the methods, the integration with wearables (e.g., to monitor physical activity, heart rate, or biomarkers),[3,40] computer adaptive testing,[41] and ecological cognitive testing[3,42] show potential for experience sampling methods research in palliative care.

Building on the promising findings of our pilot study, we intend to conduct the same protocol on a larger scale to provide more comprehensive evidence on the methods' feasibility, burden, and scientific and clinical value.[27] The larger study will explore the optimal ways in which experience sampling methods should be used in people with advanced cancer, in both research and clinical practice, and it will investigate factors influencing missed assessments or low adherence, such as high symptom burden.

Conclusion

Experience sampling methods hold promise for uncovering the symptoms, concerns, and well-being of people with advanced illness in their everyday lives. Our pilot study among people with advanced breast or advanced lung cancer confirmed this potential, demonstrating the feasibility, acceptability, and ability of these methods to capture fine-grained fluctuations in critical patient experiences. Future research is needed to assess the methods' feasibility in other populations with advanced illness.

Ethics and dissemination

This study received ethics approval by the ethics committees of the University Hospitals Brussels (BUN: 1432023000043) and Ghent (ONZ-2023-0136) and was conducted in accordance with the Declaration of Helsinki and applicable Belgian and European legislation.

Acknowledgements

We sincerely thank all the participants of the reported pilot study.

Conflicts of interest

The authors declare no conflicts of interest.

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Data management

All data is stored on secured servers of the first author's host institution and is available upon reasonably request.

Supplementary materials

Supplementary material 1: The Experience Sampling in Advanced Cancer Questionnaire (ESM-AC).
Supplementary material 2: Descriptive statistics for all follow-up questionnaire items regarding acceptability and usability of the method.
Supplementary material 3: Changes made to different properties of the method after the pilot experience sampling method study.
Supplementary material 4: Spaghetti plots of participant responses across assessments, for all continuous items.

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CHAPTER 6

Uncovering Fluctuations in Daily Symptoms and Well-being Among People with Advanced Cancer: An Experience Sampling Methods Study

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This chapter is based on: Geeraerts, J., Pivodic, L., de Nooijer, K., Rosquin, L., Decoster, L. Fontaine, C., Joris, S., Crombez, G., Naert, E., De Ridder, M., Van den Block, L. Uncovering Fluctuations in Daily Symptoms and Well-being Among People with Advanced Cancer: An Experience Sampling Methods Study. (in submission at Palliative Medicine, 2025)

Abstract

Background

Experience sampling methods are largely unexplored but may offer detailed insights into the daily experiences of people with advanced cancer. The methods involve completing multiple self-report questionnaires per day for several days, usually via smartphones.

Aim

To evaluate feasibility and acceptability of experience sampling methods in advanced cancer, and its potential to uncover moment-to-moment symptom and well-being fluctuations.

Design

Observational study including baseline measurement, a 7-day experience sampling methods period with up to 10 assessments per day, and follow-up measurement. We evaluated feasibility through response data, and acceptability through a follow-up questionnaire measuring burden, ease-of-use, instruction clarity, and measurement reactivity. We analyzed fluctuations using within-person standard deviations.

Setting/Participants

We invited 79 people with advanced breast or lung cancer via two Belgian hospitals; 40 (51%) enrolled.

Results

Thirty-seven of 40 participants provided 1,703 valid (71% of 2,400 scheduled) experience sampling methods assessments. On 7-point scales, participants reported low burden (M=2.1, SD=0.8), high ease-of-use (M=5.6, SD=1.2) and instruction clarity (M=6.5, SD=0.5), and minimal measurement reactivity (M=1.3, SD=0.3). On 0-100 scales, we observed the greatest means of within-person fluctuations across days for tiredness (M_{iSD}=16.7, SD=7.7), feeling relaxed (M_{iSD}=13.0, SD=7.3), and activity limitations (M_{iSD}=12.4, SD=9.9). Higher mean symptom intensity generally corresponded with greater within-person fluctuations.

Conclusion

Experience sampling methods proved feasible and acceptable for use by people with advanced cancer, effectively capturing individuals' unique symptom and well-being fluctuations in daily life. The methods are a promising avenue to enhance personalized care and improve quality of life by revealing the mechanisms behind individuals' fluctuations.

Introduction

Advanced cancer and its treatment often cause a variety of symptoms and mental distress.[1–3] Accurately understanding and monitoring these patient experiences is important for the provision of patient-centered care. Traditionally, these experiences have been assessed using patient-reported outcome measures (PROMs) – standardized tools that typically require patients to remember and aggregate their experiences across a period (e.g., "During the past 7 days, I felt tired"). While PROMs provide valuable insights, they cannot fully capture patients' real-time experiences and they lack insight into patients' daily lives due to their traditional approach of assessing patients at single time points or over lengthy intervals. PROMs also fail to capture the interplay between patients' experiences and determining contextual factors in daily life, such as the social company they keep, or activities they perform. Yet, such knowledge is crucial to advance patient-centered care in oncology, as it provides guidance on how to best support individual patients.

Experience Sampling Methods (ESM), also called ecological momentary assessments, have been developed in domains such as mental health research to study time-varying experiences as they occur in daily life.[4] These methods typically require people to complete multiple self-report questionnaires per day for several days or weeks, usually via smartphones. These questionnaires often measure experiences and their context in the moment, e.g., "At this moment, I feel tired".[4] Compared to traditional retrospective PROMs or qualitative interviews, ESM enable capturing the fluctuations of patient experiences in daily life, improve ecological validity, and reduce recall biases.[4]

Given the potential of ESM to uncover patient experiences in daily life,[5] studies in oncology have started using these methods.[6,7] A 2024 review identified 41 studies performed in people with cancer.[7] However, only a few were conducted among people with advanced cancer, and no studies used intensive assessment schedules (e.g., 10 assessments per day).[7] Most of the studies prompted participants only once or twice per day.[7] Although intensive assessment schedules may better capture fluctuations in daily life, their feasibility and potential burden on participants with advanced cancer is unknown. Therefore, it is important to empirically balance the benefits of ESM against its potential pitfalls.

In this study, we aim to evaluate the feasibility and acceptability of using ESM among people with advanced breast or lung cancer and its potential to uncover fluctuations in symptoms and well-being in daily life.

Methods

Study design

We performed a 7-day observational ESM study, with 10 assessments per day, using a validated smartphone-based questionnaire that measured symptoms and well-being of people with advanced breast or lung cancer.[8]

The study was approved by the ethics committees of the University Hospitals of Brussels and Ghent. Participants provided written informed consent. The study protocol was published elsewhere.[9] We followed the adapted STROBE Checklist for Reporting Ecological Momentary Assessment Studies.[10]

Participants, setting, and recruitment

We recruited people undergoing treatment or follow-up at the University Hospitals of Brussels and Ghent and collected data between September 2023 and March 2024.

The treating physician assessed eligibility criteria. Inclusion criteria were: (1) diagnosis of stage III or IV lung cancer or stage IV breast cancer, (2) aged 18 years or older, (3) Dutch-language proficiency, and (4) Eastern Cooperative Oncology group performance status of ≤2.[11]

Exclusion criteria were: (1) major difficulties or insufficient cognitive ability to participate in the study, (2) any psychiatric disorder that might hinder participation due to expected burden or unreliable responses, (3) uncorrectable hearing or poor vision, or (4) having participated in the ESM questionnaire's development or pilot study.[5,8]

We used stratified sampling to include 4 equally-sized sub-groups based on age (<70 or ≥70 years) and primary tumor site (breast or lung cancer). This sampling addressed the common under-representation of older adults.[7,12] We included these tumor types as they have relatively high prevalence, mortality rates, and symptom burden.[2,3,13]

We planned to include 40 participants, equaling 2400 scheduled assessments across 7 days. Based on previous research, this sample size is expected to be sufficient to test the feasibility and acceptability of the method.[7,14]

Outcomes

To study feasibility, we evaluated: (1) study enrollment rates (consenting divided by invited participants); (2) attrition rates (withdrawing divided by consenting participants);

(3) compliance rates (completed divided by scheduled assessments) and associations with participant characteristics, time, and symptoms and well-being levels; (4) latency (time between smartphone beep and questionnaire opening); (5) ESM questionnaire completion times; (6) attentiveness of responding as assessed by ESM and follow-up questions; and (7) accidental response scale reversal. To study acceptability, we evaluated: (1) follow-up questionnaire responses regarding burden, ease-of-use, instruction clarity, measurement reactivity (i.e., measurements' influence on reported experiences), and (2) responses to the ESM questionnaire's momentary burden item.

We used the participants' responses to the ESM questionnaire to explore the potential to capture within-person fluctuations in symptoms and well-being within and across days.

Measures and procedures

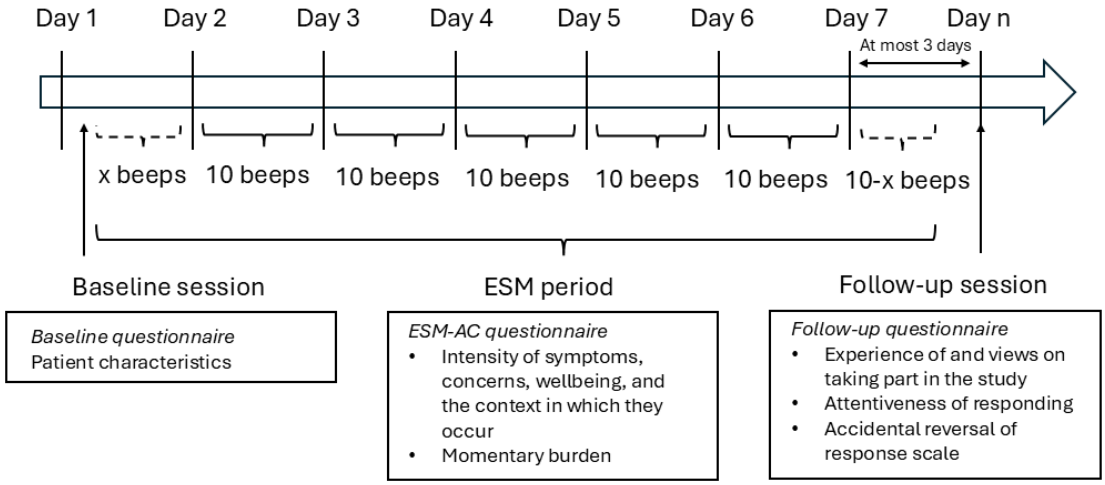
To measure symptoms and well-being with ESM we previously developed and content-validated the Experience Sampling Methods for People Living with Advanced Cancer (ESM-AC) questionnaire with people with advanced breast or lung cancer and healthcare professionals.[5,8] Study questionnaires and ESM app interface are presented in Supplement 1.[15]

The ESM-AC questionnaire measures the intensity of symptoms and well-being in-the-moment across physical, psychological, social, and spiritual-existential domains, alongside global well-being on '0–100' visual analogue scales. For instance, response options of the item "At this moment, I feel tired" ranged from 0 = "Not at all" to 100 = "Very much". The questionnaire also measures the momentary context and the experience of filling in the questionnaire, including momentary burden, using yes/no and multiple-choice response options. It has 29 to 33 items, depending on participants' responses. The first and last assessments of each day uses morning (30-34 items) and evening (34-39 items) versions of the questionnaire. The questionnaire also contains a supplemental list of experiences from which participants can (at baseline) select items that are meaningful to them (at baseline).

The study was conducted over 7 consecutive days per participant (Figure 1), starting with a baseline session, followed by an ESM period, and a follow-up session. At baseline, participants completed a questionnaire surveying gender, age, social living situation, education level, employment status, cancer diagnosis, current treatment, smartphone ownership and use,[16,17] attitudes towards scientific study participation, activities of daily living (shortened version of Barthel-Index),[18] and instrumental activities of daily living (Lawton IADL).[19] We provided participants with a Motorola e20 smartphone (Android operating system), training in using the device to fill in the ESM-AC questionnaire in the

m-Path application,[8,15] and a take-home manual.[9] We scheduled a follow-up session for 7 to 10 days after baseline.

Figure 1. Study measures and procedure.



Abbreviations. ESM = Experience Sampling Methods; ESM-AC = Experience Sampling Methods for People Living with Advanced Cancer.

On Day 1, participants received up to 10 prompts ('beeps') to complete the ESM-AC questionnaire (Figure 1). Per participant, 60 assessments were scheduled over 6 days (10 beeps per day). If fewer than 10 beeps occurred on the baseline day due to the session's timing, the remaining assessments were scheduled on Day 7. Auditory beeps, lasting approximately 30 seconds, were randomly timed within 10 time-blocks per day, at least 30 minutes apart, starting 1 hour after waking and ending 1 hour before sleep (both individually determined at baseline). After the first day, JG or LR phoned participants to check if they required help completing the questionnaire. Throughout the study, the researchers' help was available via phone and email.

During the follow-up session, we interviewed participants using a follow-up semi-structured questionnaire, measuring participants' study experiences (using 7-point Likert scales), including perceived burden, the methods' ease-of-use, instruction clarity, and measurement reactivity.[20,21] Finally, the researcher discussed with participants a visual summary of their ESM-AC questionnaire responses (example in Supplement 2).

Data analyses

To assess feasibility and acceptability outcomes, we calculated descriptive statistics. We used simple linear regression to analyze compliance as a function of participant characteristics, time, and symptom and well-being levels. We used qualitative content analysis to identify categories in participants' reasons for missing assessments.[22]

To study fluctuations, we calculated descriptive statistics, including averages, within-person standard deviations, and intra-class correlation coefficients (ICC; i.e., between-person variability divided by the sum of between and within-person variability). We also calculated floor and ceiling effects (the proportion of participants that scored 15 or lower, or 85 or higher, 80% of the time, respectively),[23] and created timeseries graphs for ESM-AC questionnaire responses. We conducted statistical analyses and visualizations in R version 4.1.1 (R Project for Statistical Computing).

Results

Participant characteristics

Forty of 79 (50.6%) invited persons consented to participate (Figure 2). The mean age was 66 (SD=10.5) years (Table 2). Twenty-nine (72.5%) females participated. Most declined due to no time or interest. One participant dropped out after 2 days, due to stress from repetitive questions. On average, participants owned smartphones for 10 (SD=7.4) years and felt confident using them (M=3.7; SD=1; 1="Not at all", 5="Very much"). Four participants added an item to the ESM-AC questionnaire (Supplement 1), one of them selected from the supplementary item list.

Figure 2. Flowchart of enrollment, compliance, retention, and inclusion in analysis.

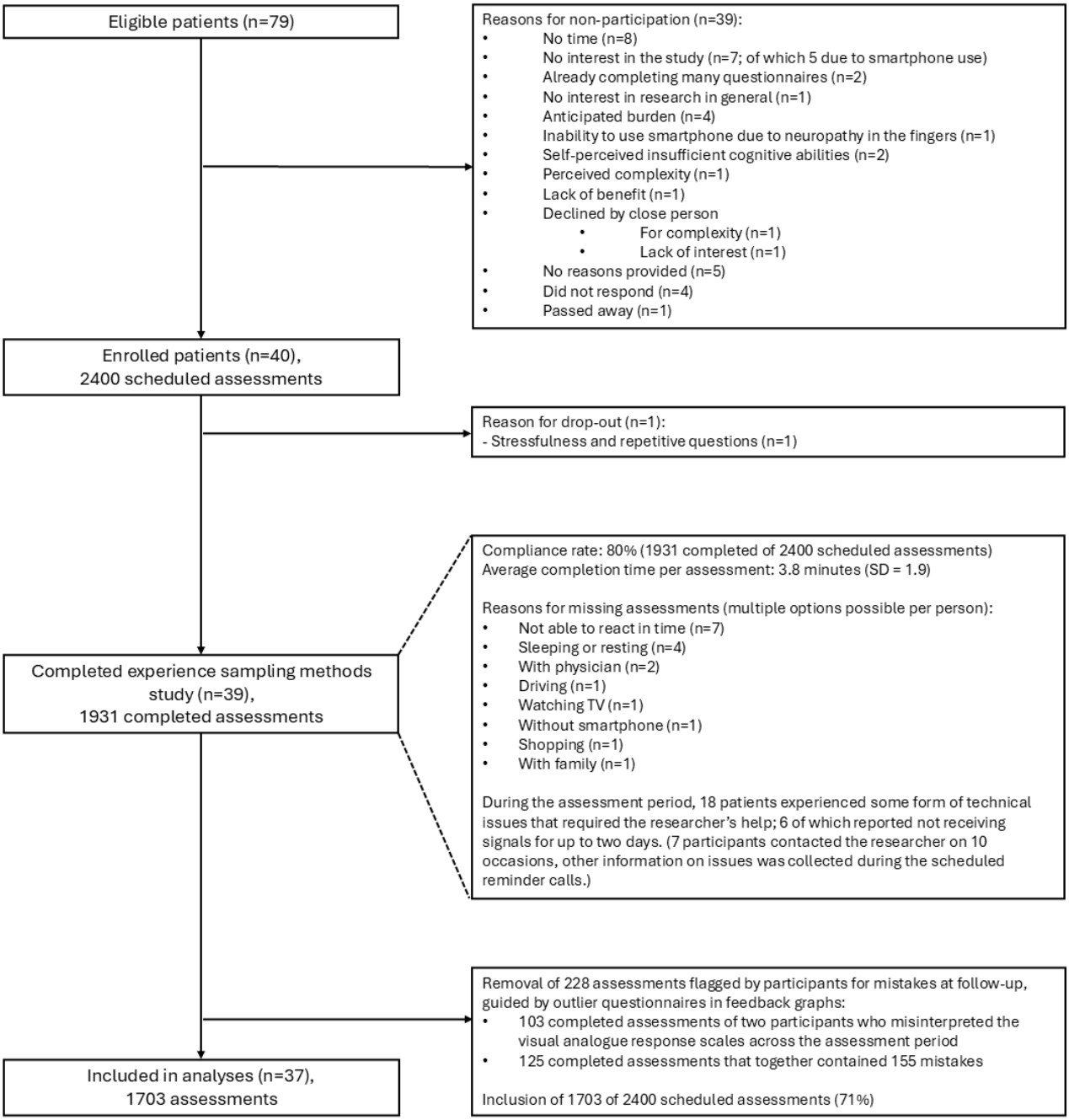


Table 1. Baseline participant characteristics.

Characteristic	N = 40
Gender, No. (%)	
Male	11 (27.5)
Female	29 (72.5)
Age, y	
Mean (SD)	66.3 (10.5)
Range	35 - 83
Social living situation, No. (%)	
Home, alone	7 (17.5)
Home, with partner/children/other	33 (82.5)
Educational level, No. (%)	
Lower secondary	5 (12.5)
Upper secondary	13 (32.5)
Higher college education	22 (55)
Employment status, No. (%)	
Professionally active	5 (12.5)
Not professionally active	35 (87.5)
Cancer diagnosis, No. (%)	
Stage III or IV lung cancer	20 (50)
Stage IV breast cancer	20 (50)
Actively receiving anti-cancer treatment, No. (%)	
Chemotherapy	9 (22.5)
Immunotherapy	9 (22.5)
Anti-hormonal therapy	6 (15)
Targeted therapy	4 (10)
Radiation therapy	1 (2.5)
Combined therapy	4 (10)
None	7 (17.5)
Self-rated years of smartphone ownership, mean (SD)	10 (7.4)
Self-rated hours spent using smartphone daily, mean (SD)	1.6 (1.5)
Self-rated confidence using smartphone (1 = "Not at all", 5 = "Very much"), mean (SD)	3.7 (1)
Attitude towards participation in scientific studies (1 = "Completely disagree", 10 = "Completely agree"), mean (SD)	
For improvement of patient care in general	9.6 (0.8)
Because of interesting study and research question	8.6 (1.4)
To help future patients in similar situation	9.5 (0.8)
To help with monitoring own symptoms and well-being	6 (3.1)
Activities of daily living (Barthel-index; 0-20 scale), mean (SD)	19.6 (1.2)
Lawton instrumental activities of daily living (0-14 scale), mean (SD)	12.7 (2.1)

Feasibility

We included 1703 of 2400 (71%) scheduled assessments of 37 out of 40 enrolled participants (Figure 2). From the ESM analyses we removed one participant who dropped-out, two participants who misinterpreted response scales (aged 81 and 82), and whole

ESM-AC questionnaires that participants flagged for mistakes at follow-up. No assessed participant characteristics, time variables, or symptoms and well-being scores significantly affected compliance rates.

The mean time from beep to opening the questionnaire was 37 (SD=66) seconds, requiring 3.8 (SD=1.9) minutes to complete the questionnaire. The mean self-reported attentiveness measured with the ESM-AC was 90.2 (SD=10; 0="Not at all", 100="Very much") and 6.7 (SD=0.6) at follow-up (1="Never", 7="Always"). Participants thought they rarely made a mistake by reversing the ends of the response scale of the ESM assessments (M=2.1, SD=1.5; 1="Never", 7="Always"). In total, participants indicated consciously missing an assessment on 17 days. Most cited reasons related to doing activities (Figure 2).

Acceptability

Means for items surveying burden-related study experiences ranged from 1.4 to 3.6 (1="Completely disagree", 7="Completely agree"), from 4.3 to 6.6 for ease-of-use of the methods, from 6 to 6.9 for instruction clarity, and from 1.1 to 1.5 for reactivity to measurements (Table 3). During the ESM period, participants did not find it disturbing to fill in the questionnaire (M=13.6; SD=17.2; 0="Not at all", 100="Very much") and reported it did not require much effort (M=8.4; SD=13.8).

Table 2. Participants' evaluation of the acceptability of using the experience sampling methods. (N=40)

	Mean across participants	**Standard Deviation**
Questions from the follow-up questionnaire (*1 = "Completely disagree", 7 = "Completely agree")*		
Burden		
Answering the questionnaires on the phone interrupted my daily routines.	2.5	1.9
I found it embarrassing if the signal to complete the questionnaire went off in the proximity of other people.	1.4	1.4
I thought it was enjoyable to use the application.*	4.3	1.3
I thought it was stressful to use the application.	1.6	1.4
My motivation to answer the beeps decreased during the past week.	2	1.9

	Mean across participants	Standard Deviation
Questions from the follow-up questionnaire (*1 = "Completely disagree", 7 = "Completely agree"*)		
This study was tiring for me.	1.5	1.3
The questionnaire became boring during the past week.	3.6	2.3
I became irritated while completing the questionnaire.	1.6	1.4
I thought the number of beeps per day was too many.	2.8	2
I thought the study period of 6 days was too long.	2.1	1.8
If there were some weeks in between, I would like to complete the digital questionnaire several times a day for another week as part of this study.*	5.6	2
Ease-of-use		
It was easy to complete the questionnaire on the phone.	6.6	1.2
Sometimes I needed to hurry to be able to fill in the questionnaire on time.*	2.7	2.2
I thought it was easy to remind myself to always take the phone with me during the study period.	5.8	2
Instruction clarity		
The training at the start of the study period was sufficient to use the app for a week.	6.9	0.5
I felt supported by the researchers during the study period.	6.6	0.9
During the past week I had the feeling this study is important.	6	1.4
Reactivity to measurements		
Due to regularly completing the questionnaire I felt different than usual.	1.5	1.4
Due to completing the questionnaires on the phone I did things I wouldn't normally do.	1.1	0.6
Questions from the experience sampling method questionnaire, presented at every beep ***(Visual Analogue Scale: 0="not at all", 100="a lot") – Momentary burden***		
I found it disturbing to fill in this questionnaire now.	13.6	17.2
It cost me effort to complete this questionnaire.	8.4	13.8

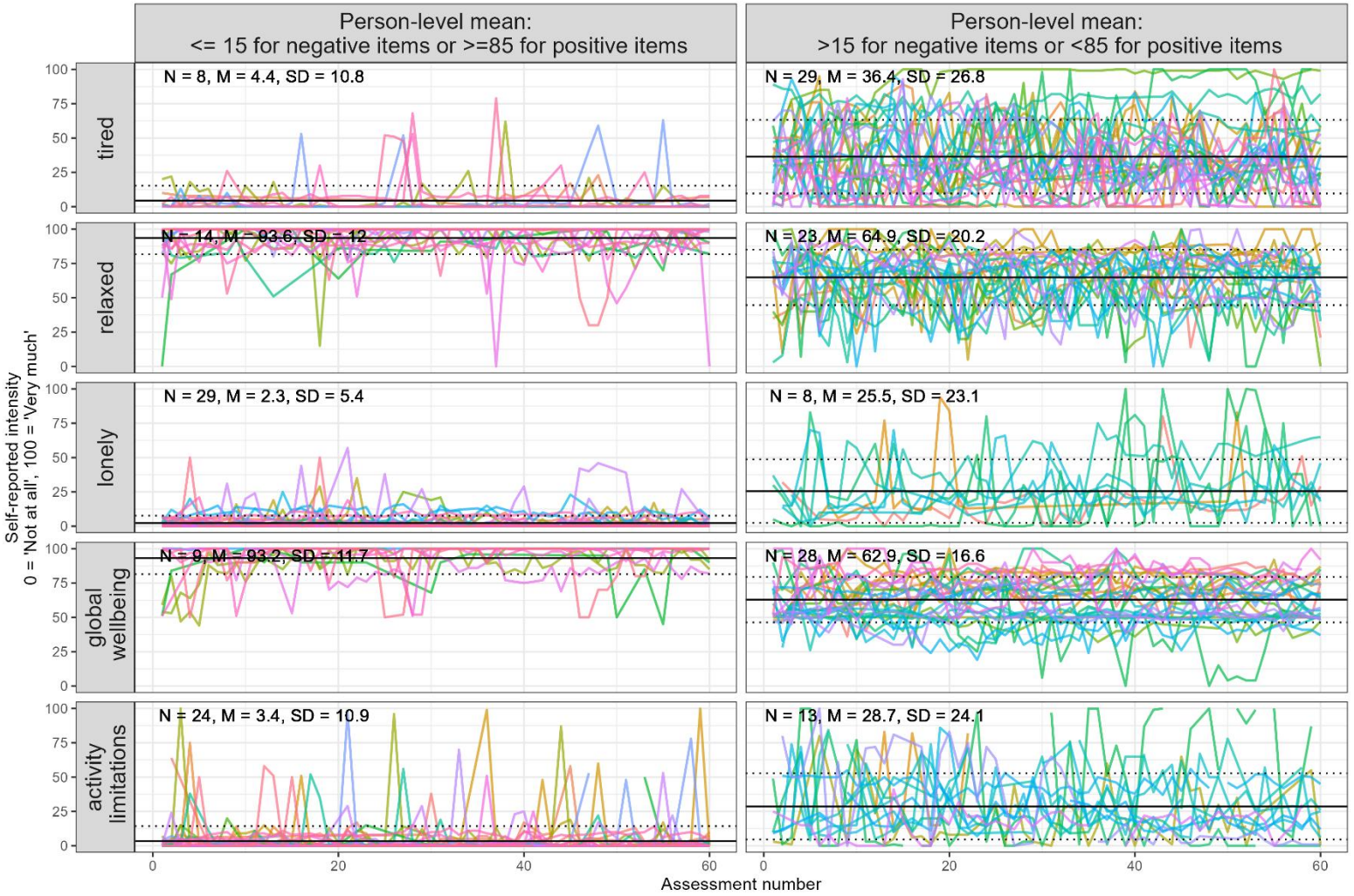
* item needs to be reverse-scored.

Fluctuations in symptoms and well-being in the daily life context

The analyses revealed variability in participants' symptom and well-being across the week, with mean levels and fluctuations varying between individuals and experiences. The mean of person-means of symptoms and well-being on the physical domain ranged between 4.2 (SD=5.5) for nausea and 29.2 (SD=20.9) for tiredness (0-100 scale; eTable 1 and eFigure 1 in Supplement 3). For the psychological domain, mean intensity of negative experiences ranged between 6.4 (SD=8.2) for anxiety and 11.8 (SD=13.7) for feeling worried, whereas mean intensity of positive experiences ranged between 61.0 (SD=25.3) for feeling energized and 77.4 (SD=16.7) for feeling content. Loneliness and global well-being had means of 7.4 (SD=11.0) and 70.3 (SD=17.1), respectively. Experiences fluctuated over time, with patterns differing between participants (Figure 3; complete list in eFigure 2 of Supplement 3). Regarding within-person standard deviations, tiredness (M_{iSD}=16.7, SD=7.7), feeling relaxed (M_{iSD}=13.0, SD=7.3), and activity limitations (M_{iSD}=12.4, SD=9.9) fluctuated the greatest, and nausea (M_{iSD}=4.5, SD=5.8), breathing problems (M_{iSD}=4.8, SD=5.1), and anxiety (M_{iSD}=5.4, SD=6.1) fluctuated least. Within- versus between-person variability was highest for nausea (ICC=0.32) and lowest for feeling energized (ICC=0.73).

Floor effects (scores concentrated at low-end) and ceiling effects (high-end scores) were common. The proportion of floor effects ranged from 0.03 (feeling energized) to 0.84 (nausea), whereas ceiling effects ranged from 0.03 (feeling tired) to 0.32 (feeling content). For instance, 24 participants scored on average 15 or lower on limitations with activities. Moreover, participants with lower means visually showed lower variability than those with higher means (Figure 3). Post-hoc correlations confirmed that, for positive items, higher person-means associated with lower within-person variability (mean *r*=-.20, SD=.15); for negative items, higher person-means associated with higher within-person variability (mean *r*=.68, SD=.15). Thus, worse-rated symptoms and well-being exhibited stronger fluctuations over time. Participants completed assessments in various contexts, but mostly at home (79.5%), doing passive leisure activities (30.8%), and with their partner present (46.4%; details in eTable 2 in Supplement 3).

Figure 3. Tiredness, feeling relaxed, loneliness, global well-being, and activity limitations over time, grouped by mean self-reported intensity.*



*Note to Figure. The left panels display participants with means of 15 or lower for negative experiences (or 85 or higher for positive experiences), whereas the right panels show of the rest of the participants (with more severe scores). We selected the items with the highest within-person variability for each of the domains that were assessed multiple times per day. Solid lines indicate means, dotted lines indicate one standard deviation from mean.

Discussion

High-intensity ESM are feasible and acceptable for assessing the symptoms and well-being of people with advanced breast or lung cancer in the context of daily life. Our findings showed a 71% rate of viable completed assessments, only 1 study drop-out, high self-reported attentiveness during responding, and minimal expected response mistakes. Participants reported positive study experiences: minimal burden, low measurement reactivity, easy-to-use methods, and clear instructions. Most would participate again, and ecological validity was supported as participants reported not changing their activities due to study participation. Overall study enrollment was 50%. Crucially, ESM precisely captured participants' fluctuations in symptom and well-being experiences, especially at more severe intensity levels. For instance, participants with high scores for tiredness showed stronger fluctuations over time than those with lower scores. Visually distinct fluctuation patterns were apparent, with some participants showing stability at high levels, while others fluctuated regularly or irregularly.

Despite the high-intensity assessment schedule, our findings support the feasibility and acceptability of ESM. This aligns with findings from other lower-intensity studies in advanced cancer populations or ESM studies in other fields.[7,24]. Our compliance rate matched the mean 79% rate of the latter.[7,24] The positive study experiences also echoed our pilot study findings.[5,9] Encouragingly, compliance was unaffected by age or smartphone experience, suggesting feasibility for older adults and those with little smartphone experience. However, two of the oldest participants provided invalid data due to misunderstanding the response scale. Furthermore, the over-representation of highly educated and digitally skilled participants suggests barriers for less digitally skilled, less educated individuals, potentially limiting older adult participation. The 50% enrollment rate further reflects these points and suggests possible selection biases when using digital ESM. Offering pen-and-paper questionnaire alternatives could enhance inclusivity.[25] For participants in the study, training and check-up calls likely improved their study experiences and data quality.[25]

The observed fluctuations in symptoms and well-being, such as for tiredness, pain, positive affect, and limitations with activities, clearly reflect their dynamic nature.[26,27] This underscores the advantage of ESM over traditional PROMs and interviews that are unable to capture these daily-life dynamics. ESM adds a fine-grained temporal and ecologically-valid dimension to symptom and well-being research and the observed fluctuations raises key questions about what drives them – critical questions for improving patient-centered care. As seen in fields such as mental health research, ESM could offer a strong tool for disentangling determining factors of symptoms and well-being fluctuations.[4] For instance,

ESM can uncover whether people's preceding experiences, thoughts, behaviors, and daily contexts influence currently experienced levels.[4] This approach addresses calls for more comprehensive symptom assessment and deeper understanding of underlying mechanisms,[3,28] including in clinical trials.[5] Such fine-grained insight could also enable early, targeted interventions for treatment-related toxicity.

We observed the strongest fluctuations in scores among participants with higher scores for certain symptoms or lower scores for well-being. For participants with generally low symptom scores or higher well-being throughout the seven-day observation period, fluctuations were less notable. This suggests that ESM could be most clinically meaningful for people who express moderate or severe burden from certain symptoms or concerns. ESM might then provide a deeper understanding of the experienced patterns for a specific person, which is needed to guide personalized treatment and support, and to explore personalized intervention targets.[4,27,29] For persons whose symptoms are effectively managed or who experience limited side effects from treatments, using traditional PROMS regularly or prompting persons to discuss their symptoms and concerns during consultations might be sufficient.

As ESM is novel in oncology, further refinement is needed. Feasibility and acceptability should be further explored in other cancer types or stages and using other study designs. Extending assessments over more days with less intensive schedules may yield similar amounts of data while improving enrollment and generalizability. Furthermore, people with advanced cancer and healthcare professionals' perspectives on the clinical possibilities of capturing moment-to-moment fluctuations in experiences should be explored. Further research could also investigate which magnitude of fluctuations can be perceived as clinically important by people with cancer. For instance, by using a within-person anchor approach.[30]

This study was the first to use an intensive ESM assessment schedule in advanced cancer, providing unique insights into symptom and well-being fluctuations over time. The ESM-AC questionnaire was specifically developed and content-validated for people with advanced breast or lung cancer and we used the latest methodological guidance for ESM studies.[8] The study also had limitations. First, we included people with a relatively high functional status, limiting generalizability to those with greater physical impairment or symptom burden. Second, missing assessments during high-burden periods or during activities could lead to underestimations of both. However, participants did not cite burden as a reason for missing assessments. Third, the single-item ESM-AC constructs, while brief, were sensitive to mistakes by participants. Discussing visual feedback with participants helped identify and exclude erroneous responses. Lastly, although the 80% completion

rate and the high willingness of most participants to participate again suggest genuine positive experiences, the researcher's presence during follow-up could have induced socially desirable responses of participants' study experiences.

In conclusion, high-intensity ESM proved feasible and acceptable for people with advanced breast or lung cancer, with most reporting positive study experiences. ESM effectively captured individuals' unique daily symptoms and well-being fluctuations, especially when more severe intensity levels were experienced. ESM could enhance personalized care and improve quality of life by revealing the mechanisms behind these fluctuations.

Ethics and dissemination

This study received ethics approval by the ethics committees of the University Hospitals Brussels (BUN: 1432023000043) and Ghent (ONZ-2023-0136) and was conducted in accordance with the Declaration of Helsinki and applicable Belgian and European legislation.

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Conflicts of interest

The authors declare no conflicts of interest.

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Data management

All data is stored on secured servers of the first author's host institution and is available upon reasonably request.

Supplementary materials

Supplementary material 1: English translation of Dutch used questionnaires (not using identical lay-out) and additional information on ESM-AC questionnaire.
Supplementary Material 2. Visual feedback provided during the interviews (English translation, some formatting has changed in translation process)
Supplementary Material 3. Visual analogue scale item response distributions

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CHAPTER 7

A Comparison of In-The-Moment and Retrospective Patient-Reported Outcome Measures in Advanced Cancer

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Abstract

Purpose

Understanding how to optimally measure symptoms and wellbeing of people with advanced cancer is crucial for supporting patient-centered care. We aimed to (1) compare repeated in-the-moment assessments (experience sampling methods/ESM) and retrospective assessments (traditional patient-reported outcome measures/PROMS) of symptoms and well-being among people with advanced breast or lung cancer; and (2) explore factors associated with discrepancies between these methods.

Methods

In an observational study among people with advanced breast or lung cancer, participants completed up to 60 in-the-moment ESM assessments over 7 days, followed by a 7-day recall (i.e., retrospective) questionnaire covering the same period. We compared in-the-moment and retrospective scores of 16 symptom and wellbeing items visually and through correlations. We examined factors associated with discrepancies using linear regression.

Results

We analyzed 1676 in-the-moment assessments from 36 participants. Visually, higher in-the-moment scores were associated with higher retrospective scores across the sample. But, participants with identical retrospective scores often had different means (especially when they had higher recalled scores) and fluctuation patterns of in-the-moment scores. Item correlations between in-the-moment and retrospective scores ranged between .24 and .70. The largest discrepancies occurred for pain (*Mdiff*=-13.2) and tiredness (*Mdiff*=-12.4). Several parameters of in-the-moment scores and participants' active treatment status were associated with discrepancies.

Conclusion

Individuals' retrospective symptom and wellbeing scores positively correlated with their in-the-moment scores over one week. Pain and tiredness showed the largest discrepancies. In-the-moment scores revealed considerable variability between individuals and fluctuations over time, which may be relevant to assess depending on the clinical or research objective.

Background

Given the high impact of advanced cancer and its treatment,[1,2] the assessment and monitoring of patients' symptoms and wellbeing is critical to inform and optimize patient-centered care. Traditionally, assessments are done during consultations or through patient-reported outcome measures (PROMs), which typically ask about symptoms or wellbeing over the past few days or weeks, e.g., "During the past 7 days, how tired were you?".[3–5] Similarly, clinical consultations often rely on patients' retrospective symptom reports spanning weeks or months since last consultation. By requiring patients to recollect and aggregate their symptoms and wellbeing over a certain period of time, these approaches are prone to memory or recall biases. For instance, the peak-end-rule states that recollections are shaped by the most intense and most recent moments of an experience over a period.[6–8]

To minimize such biases, ecological self-report tools assess symptoms and wellbeing in the moment in daily life (e.g., "At this moment, I feel tired").[9,10] Experience sampling methods (ESM) or ecological momentary assessments are a prime example, as they typically prompt patients multiple times per day over several days to complete a self-report questionnaire, usually via smartphones. These methods can capture the prevalence and fluctuations of participants' feelings, thoughts, and/or behaviors in relation to daily life.[11,12] For this purpose, ESM are increasingly used in oncology research, but their use among people with advanced cancer remains understudied.[9,13]

No studies in advanced cancer have directly compared in-the-moment ESM assessments with traditional retrospective measures.[9,14] Yet, understanding their relationship can shed light on when their use is appropriate. For instance, given the concern of participant burden when using ESM's frequent assessments,[13] knowledge of its added value over traditional PROMs is essential. Furthermore, it is unclear how recall biases, such as those described by classic cognitive theories, shape symptoms and wellbeing reports in advanced cancer.[6–8] Greater insight into these factors could improve interpretation of symptom and wellbeing self-reports and inform future assessment strategies.

In this study, we aimed to: (1) compare in-the-moment and retrospective (7-day recall) assessments of symptoms and wellbeing among people with advanced breast or lung cancer; and (2) explore to what extent patient and item score characteristics are associated with score discrepancies between these methods.

Methods

Study design

As part of an observational ESM study that assessed the feasibility of ESM among people with advanced breast or lung cancer,[15] participants chronologically completed a baseline questionnaire collecting demographic and clinical information, a 7-day ESM period using in-the-moment symptoms and wellbeing assessments, and a follow-up retrospective questionnaire on the same symptoms and wellbeing content. The study's protocol and feasibility results were published elsewhere.[15,16] The study was conducted in accordance with the Declaration of Helsinki and was approved by the ethical committees of the University Hospitals of Brussels and Ghent (BUN: 1432023000043).

Study population and setting

We included patients who were treated or followed at the University Hospitals of Brussels and Ghent (Belgium) between September 2023 and March 2024. The treating physician assessed eligibility criteria. Inclusion criteria were: (1) stage III/IV lung cancer or stage IV breast cancer, because these tumor sites have relatively high prevalence, mortality rates, and symptom burden,[17–22] (2) aged ≥18 years, (3) Dutch-language proficiency, and (4) Eastern Cooperative Oncology group performance status of ≤2.[23] Exclusion criteria included: (1) major difficulties or insufficient cognitive ability limiting participation, (2) psychiatric conditions that might hinder participation due to expected burden or unreliable responses, (3) uncorrectable hearing or vision problems, or (4) prior enrollment in previous parts of the project. To address the underrepresentation of older adults in research, we created four equally sized subgroups based on age (<70 or ≥70 years) and primary tumor site (breast or lung cancer).[9,24,25] We planned to include 40 participants, equaling 2400 scheduled assessments across 7 days, considered sufficient for evaluating ESM's feasibility in the original study.[9,26]

Study procedures

After providing informed consent, participants completed a baseline questionnaire before starting a 7-day ESM period. During this period, participants were prompted up to 10 times per day at random times during waking hours to complete the content-validated Experience Sampling Methods for People Living With Advanced Cancer (ESM-AC) questionnaire.[27] This questionnaire measures symptoms and wellbeing across multiple domains, with items capturing experiences in the moment, phrased as "At this moment, I feel …". Within 3 days after completing the last ESM-AC questionnaire, participants met with the researcher and

completed a pen-and-paper follow-up questionnaire measuring the same content but phrased retrospectively: "During the past week, I felt …".

Measures

The baseline questionnaire measured participants' demographic and clinical characteristics: age, gender, educational level, diagnosis, whether or not the participant was actively receiving treatment, general anxiety and depression levels,[28] and average daily smartphone use.[15,29,30] The ESM-AC questionnaire included 16 symptom and wellbeing items across physical, psychological, social, and global domains, rated using visual analogue scales (0="Not at all", 100="Very much"; Supplementary Material 1 for all questionnaire items).[27] The follow-up questionnaire used identical symptom and wellbeing items as the ESM-AC questionnaire with 7-day recall instructions and 4-point Likert scales (1="Not at all" to 4="Very much"), aligning with the EORTC QLQ-C30 – a widely used PROM in oncology.[4]

Statistical analyses

We conducted analyses in R (version 4.1.1). To address Aim 1, we used two complementary approaches: visualizations and correlation analyses. With the visual approach, we studied participants' in-the-moment scores in relation to the different retrospective (7-day recall) scores. For each item, we grouped participants with identical retrospective scores (using the four-point Likert scale) and plotted their in-the-moment scores over time. These plots included group means and standard deviations of the in-the-moment scores to illustrate average levels and variability. Additionally, we created plots showing the mean in-the-moment score for each participant (per item) against their retrospective item score to visually explore the relationship between the two.

With the correlational approach, we statistically examined how retrospective scores were related to the in-the-moment scores for each item, i.e. by examining the correlation between the retrospective score and (a) the mean of in-the-moment scores, (b) the maximum of in-the-moment scores, and (c) the mean of in-the-moment scores on the sixth day (the final full assessment day). We chose these statistics based on earlier findings and the peak-end theory, which suggests that recollections are influenced most by peak intensity and recent experiences.[6,7,14] For each item, we calculated Kendall's tau correlations between said scores, yielding three correlations per item.[31] We bootstrapped 95% confidence intervals using 1000 replicates. Kendall's tau ranges from -1 to 1, indicating perfect negative to perfect positive agreement in rankings, respectively.

For Aim 2, we examined how participants' in-the-moment and retrospective scores differed, by calculating discrepancy scores at both the participant and item level (Supplementary Material 2 provides a visual overview of the calculations). This enabled us to explore if differences between the two methods were related to either the characteristics of the participants or the items themselves. To facilitate comparison, we rescaled retrospective scores from a 1-4 Likert scale to a 0-100 scale.

At the participant-level, we calculated one discrepancy score (i.e., signed difference between retrospective score and the mean of in-the-moment scores) for each participant for each of the 16 items. We then calculated the mean of these 16 discrepancy scores to obtain a single discrepancy score per participant, reflecting the participant's agreement between in-the-moment and retrospective scores across items.

To explore associations of these participant-level discrepancies with participant or item characteristics, we fitted simple linear regression models followed by a multivariable regression model with the significant predictors of the simple models. Participant characteristics included the 8 baseline variables, the rate of completed over scheduled assessments, cognitive complaints, and the number of days between the last ESM entry and completion of the follow-up questionnaire (within a maximum of 5 days). Item score characteristics included: participants' mean, maximum, sixth-day mean, and standard deviation of in-the-moment assessment-level symptom and wellbeing aggregation scores – defined as the mean of the 16 items per ESM assessment, with positively worded items reverse-scored to ensure consistent directionality.

At the item-level, we investigated whether certain items systematically showed greater discrepancies between in-the-moment and retrospective scores. For each item, we calculated the signed difference between each participant's retrospective score and the mean of all their in-the-moment scores. We then calculated the mean of all participants' differences to represent the items' agreement between the methods across participants. We used one-sample t-tests to determine whether these mean discrepancies significantly differed from zero.

To explore if discrepancies at the item-level were associated with characteristics of items' in-the-moment scores, we used simple linear regression. Predictors included the item's mean, maximum, sixth-day mean, and standard deviation over time (across participants). Because positive and negative discrepancies could cancel each other out and give the impression of no difference, we repeated all item-level analyses using absolute (rather than signed) differences to capture the overall magnitude of disagreement between the two measurement types.

Results

Participant characteristics

We included 1,676 valid assessments out of 2,400 scheduled from 36 of 40 participants. One participant dropped out, two misused the response options, and one completed the follow-up questionnaire too late (15 days post-ESM). The mean participant age was 65.4 (SD=10.3; Table 1).

Table 1. Participant characteristics (N=36).

Characteristics	N (%) or Mean (SD)
Gender (% female)	26 (72.2)
Age (years)	65.4 (10.3)
Living situation	
Home, alone	6 (16.7)
Home, with partner/children/other	30 (83.3)
Educational level	
Lower secondary	4 (11.1)
Higher secondary	12 (33.3)
Post-secondary non-tertiary	3 (8.3)
Bachelor's degree	7 (19.4)
Master's degree	10 (27.7)
Cancer diagnosis	
Stage III or IV lung cancer	18 (50)
Stage IV breast cancer	18 (50)
Actively receiving anti-cancer treatment	
Chemotherapy	7 (19.4)
Immunotherapy	8 (22.2)
Anti-hormonal therapy	5 (13.9)
Targeted therapy	4 (11.1)
Radiation therapy	1 (2.8)
Targeted and anti-hormonal therapy	2 (5.6)
Chemotherapy and Immunotherapy	1 (2.8)
Chemotherapy and anti-hormonal therapy	1 (2.8)
None	7 (19.4)
Self-rated hours spent using smartphone daily	1.7 (1.5)
Hospital Anxiety Depression Scale - Anxiety	4.9 (2.8)
Hospital Anxiety Depression Scale - Depression	3.6 (2.7)
Days between experience sampling methods period and follow-up session	1.1 (1.2)
Percentage of completed assessments over scheduled assessments*	82.8 (16.8)

Abbreviations. SD = Standard deviation.

*Completed assessments excluded 125 in-the-moment ESM assessments of 23 participants that they themselves flagged for mistakes at follow-up.

Mean symptom and wellbeing scores across participants

Regarding the in-the-moment scores of symptom and wellbeing items on 0 (="Not at all") to 100 ("Very much") scales, means of person-means ranged from 3.9 (SD=4.3) for feeling nauseated to 27.4 (SD=16.9) for feeling tired (see Supplementary Material 3).

For retrospective item scores (using a 4-point Likert scale; 1="Not at all", 4="Very much"), we observed the lowest mean scores for feeling anxious, lonely, nauseated, and experiencing concentration problems, (all M=1.1, SD=0.4-0.5). The highest symptom score was for feeling tired, with a mean of 2.2 (SD=0.9).

Comparison between in-the-moment and retrospective scores

Visual approach

Participants' symptoms and wellbeing scores fluctuated considerably over the 7-day period (Supplementary Material 4 presents plots of all items). Figure 1a illustrates these fluctuations for three items: feeling content, pain, and tiredness.

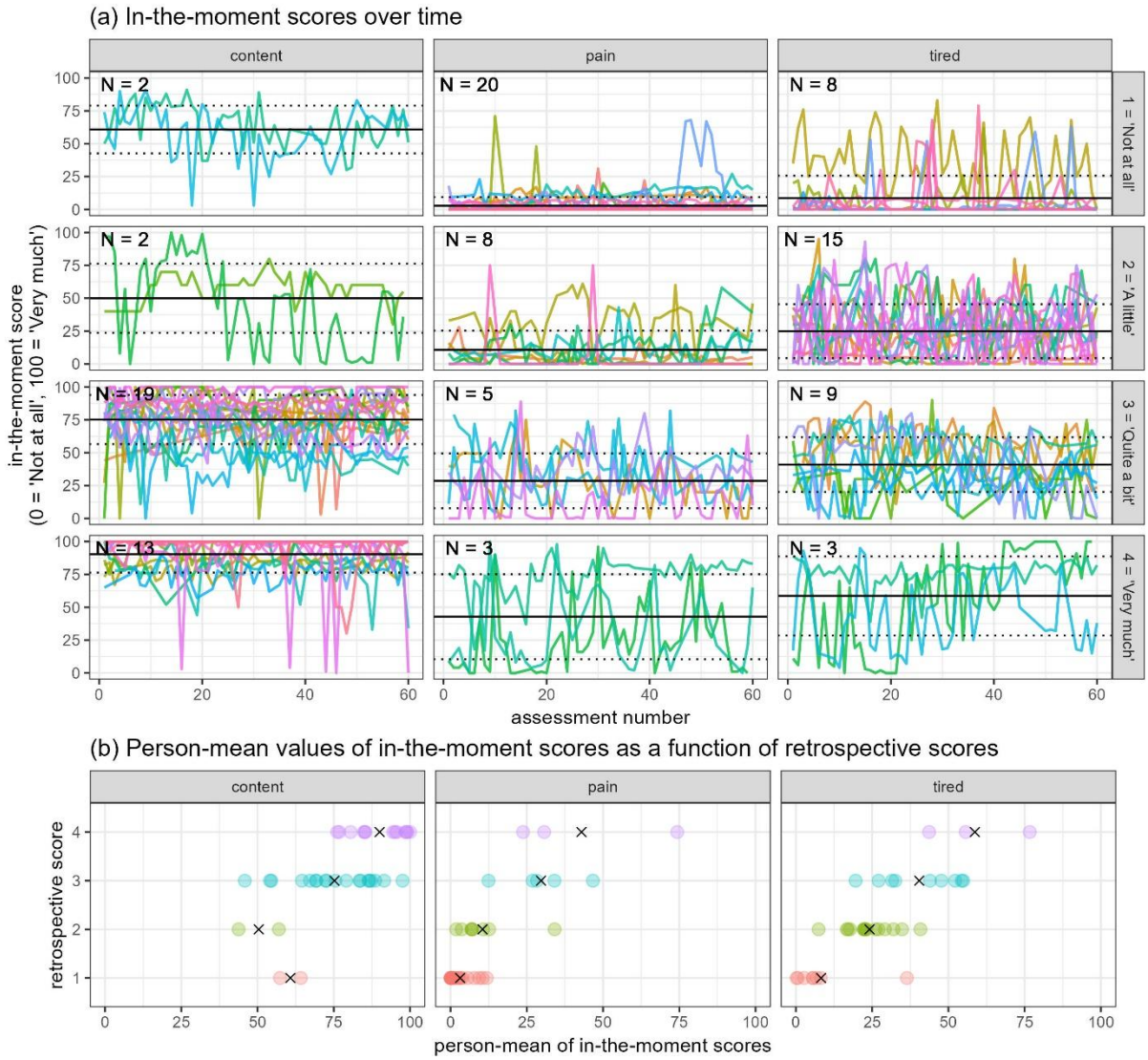
Participants who gave the same retrospective score (e.g., "Quite a bit" for tiredness) often showed very different fluctuation patterns of their in-the-moment scores over the week (Figure 1a). Conversely, some participants with different retrospective scores showed similar in-the-moment trajectories.

To examine whether average in-the-moment scores of participants were related to their retrospective scores, Figure 1b plots each participant's 7-day mean in-the-moment score against their corresponding retrospective score. Overall, participants with higher average in-the-moment scores tended to report higher retrospective scores (see Supplementary Material 5 for all items and Supplementary Material 6 for corresponding values). For example, participants who recalled high levels of tiredness generally also had high mean in-the-moment tiredness scores.

However, this association was not perfect. Participants with the same retrospective score sometimes had widely varying means of in-the-moment scores, while those with different retrospective scores could have similar mean scores. This pattern was most pronounced among participants with the highest retrospective scores. Specifically, higher retrospective scores were associated with greater variability in corresponding in-the-moment means (r=0.64, 95% CI=0.42–0.64). Thus, participants who recalled more severe symptoms or wellbeing varied more from each other in their average in-the-moment scores. We observed the greatest variability in in-the-moment means for pain (mean SD=13.5),

feeling energetic (mean SD=13.4), tiredness (mean SD=12.4), and difficulties with performing activities (mean SD=11.9).

Figure 1. Visual examples of the 36 participants' in-the-moment scores of feeling content, pain, and tired across the seven days of ESM data collection, as a function of corresponding retrospective scores.

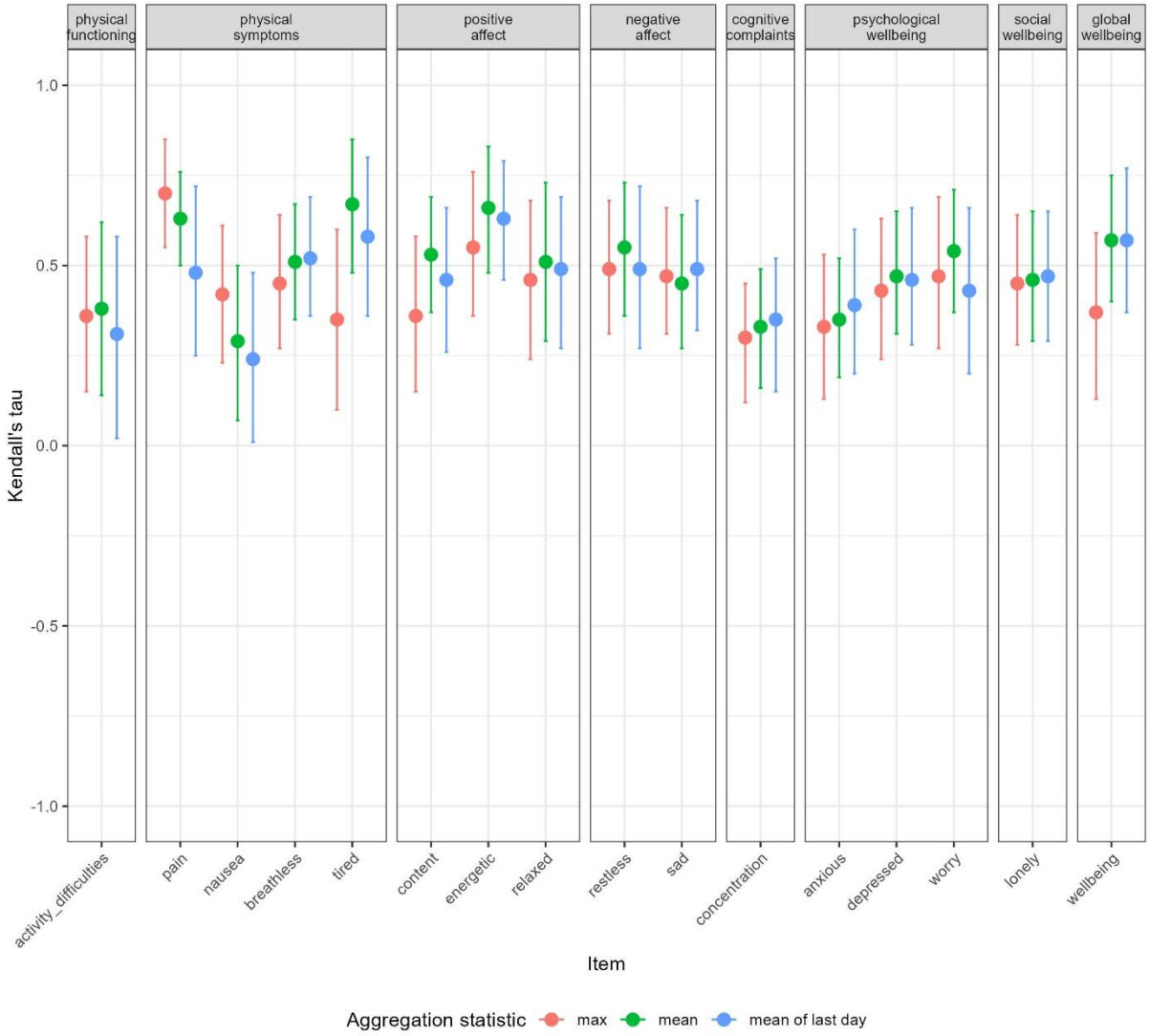


Notes. These items were selected based on their clinical relevance and because they span across multiple domains. (a) Differently colored lines represent different participants. Black full lines indicate group-means and dotted lines indicate a one standard deviation spread above and below the group-mean lines. (b) Dots represent persons' means of in-the-moment scores and crosses indicate group-means.

Correlation approach

Retrospective scores were positively correlated with the mean, maximum, and sixth-day mean of the corresponding in-the-moment symptom and wellbeing scores. All items had positive Kendall's tau correlations (Figure 2 and Supplementary Material 7 for details). On average, the correlation between retrospective scores and mean in-the-moment scores was .49 (SD=.11). The average correlation between retrospective scores and the maximum of in-the-moment scores was .44 (SD=.10), while the average correlation between retrospective scores and the sixth-day mean of in-the-moment scores was .46 (SD=.10).

Figure 2. Correlations between retrospectives scores and the mean, maximum, and mean of the sixth day of the in-the-moment symptom and wellbeing scores during the 7-day period.



Note. Dots display the Kendall's tau correlations and lines indicate bootstrapped 95% confidence intervals using 1000 replicates.

Factors associated with discrepancies between in-the-moment and retrospective scores

Participant-level discrepancies

On average, participants' retrospective scores closely matched their in-the-moment scores, as indicated by the lack of a significant overall (signed) difference between the measurement types (M=-1.6, SD=5.9, t(15)=-1.6, p=0.12).

However, exploratory analyses identified several factors that were significantly associated with the degree of discrepancy between retrospective and in-the-moment scores (Table 2 and Supplementary Material 8). In the simple regression models, discrepancies were associated with: the sixth-day mean of in-the-moment assessment-level symptom and wellbeing aggregation scores (B=-0.16, p=.04), the maximum of symptom and wellbeing aggregation scores during the week (B=-0.15, p=0.02), the standard deviation of symptom and wellbeing aggregation scores during the week (B=-0.81, p=.002), and whether participants were actively receiving treatment (B=7.51, p=.001). In the multivariable model, only active treatment status remained statistically significant (B=5.89, p=.010). This effect was not attributable to differences in symptom and wellbeing scores, as average scores did not differ by treatment status.

Table 2. Associations of participant and item score characteristics with the discrepancies between in-the-moment and retrospective scores (using signed differences).

	Regression coefficients of simple linear linear regression models				Regression coefficients of multivariable regression model with significant predictors of simple models			
Effect	Estimate	Standard error	t	p	Estimate	Standard error	t	p
(Intercept)	---	---	---	---	-4.679	2.877	-1.627	0.114
Actively receiving treatment	7.511	2.155	3.485	0.001**	5.887	2.137	2.755	0.010**
Maximum of in-the-moment assessment-level symptom and wellbeing aggregation scores[a]	-0.146	0.060	-2.453	0.019*	0.176	0.239	0.736	0.467
Mean of the sixth day of in-the-moment assessment-level symptom and wellbeing aggregation scores[a]	-0.161	0.077	-2.09	0.044*	-0.059	0.211	-0.280	0.781

	Regression coefficients of simple linear regression models				Regression coefficients of multivariable regression model with significant predictors of simple models			
Effect	Estimate	Standard error	t	p	Estimate	Standard error	t	p
Standard deviation of in-the-moment assessment-level symptom and wellbeing aggregation scores[a]	-0.808	0.245	-3.294	0.002**	-1.137	0.579	-1.965	0.058
Gender (female)	3.006	2.158	1.393	0.173	---	---	---	---
Education (tertiary)	-3.476	1.899	-1.831	0.076	---	---	---	---
Hospital Anxiety and Depression Scale - Anxiety	-0.081	0.365	-0.223	0.825	---	---	---	---
Hospital Anxiety and Depression Scale - Depression	-0.093	0.376	-0.248	0.806	---	---	---	---
Mean of in-the-moment assessment-level symptom and wellbeing aggregation scores[a]	-0.111	0.102	-1.096	0.281	---	---	---	---
Age	-0.002	0.098	-0.02	0.984	---	---	---	---
Average daily smartphone use	0.917	0.649	1.414	0.167	---	---	---	---
Diagnosis (lung cancer)	-0.42	1.986	-0.212	0.834	---	---	---	---
Cognitive complaints	-0.066	0.082	-0.8	0.429	---	---	---	---
Days between experience sampling methods period and follow-up	-0.265	0.863	-0.307	0.76	---	---	---	---
Rate of completed over scheduled assessments	-5.188	5.927	-0.875	0.388	---	---	---	---

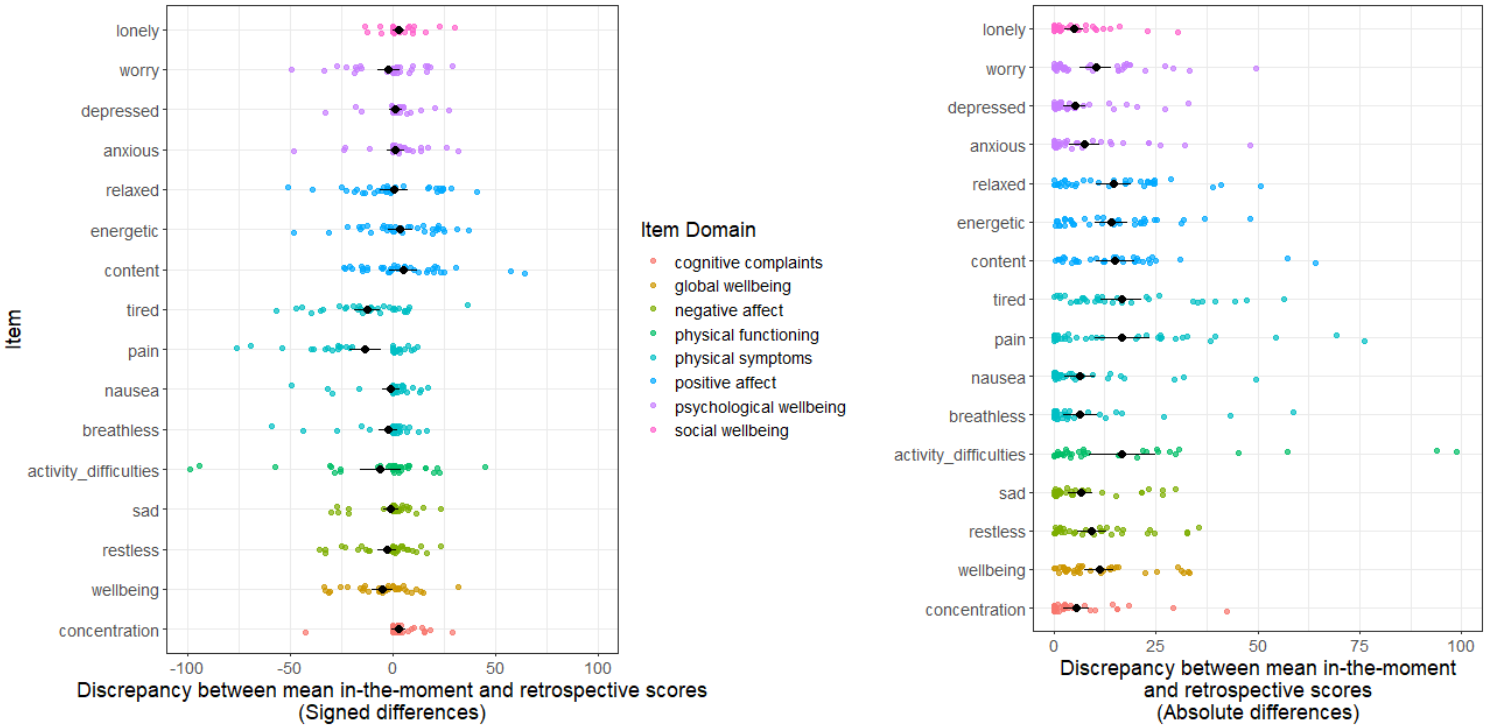
Footnotes. * ($p < 0.05$), ** ($p < 0.01$), [a]We calculated in-the-moment assessment-level symptom and wellbeing aggregation scores as the mean of the 16 symptom and wellbeing scores per experience sampling methods assessment (with reverse scoring of positive experiences).

Item-level discrepancies

Several symptoms and wellbeing items showed significant discrepancies between in-the-moment and retrospective scores (Figure 3). Using signed differences (considering the direction of the discrepancy), t-tests indicated higher scores on the retrospective questionnaire compared to in-the-moment scores for pain (M=-13.2, t(35)=-3.5, p=0.001), tiredness (M=-12.4, t(34)=-4.0, p<0.001), and global wellbeing (M=-4.9, t(35)=-2.05, p=0.05). Conversely, loneliness was rated lower retrospectively compared to in-the-moment (M=2.9, t(35)=2.2, p=0.04). Simple linear regression models revealed no significant relationships between item-level predictors and these signed discrepancies.

However, analyses using absolute differences (reflecting the size of the discrepancy regardless of direction) revealed larger discrepancies between the measurement types for items with greater averages, fluctuations, maximum values, and final-day means of in-the-moment scores. Specifically, significant predictors included: the item-level means of participants' mean (B=0.09, p=0.03), standard deviation (B=1.08, p<0.001), maximum (B=0.12, p=0.001), and mean of the sixth day of in-the-moment scores (B=0.09, p=0.03).

Figure 3. Item-level discrepancies between persons' means of in-the-moment scores and their retrospective scores.



Notes. Each colored dot represents the discrepancy between the methods for one person. Black dots indicate mean discrepancy scores, with the lines indicating their 95% confidence intervals.

Discussion

This study found substantial fluctuations in symptoms and wellbeing of people with advanced breast or lung cancer over one-week period. Visually, higher in-the-moment scores were associated with higher retrospective scores across the sample. However, mean in-the-moment scores and fluctuation patterns varied widely between individuals, even among those with identical retrospective scores. Retrospective scores were positively correlated with the mean, maximum, and sixth or last-day mean of in-the-moment scores for all items. We observed the largest discrepancies between the methods for pain and tiredness. Discrepancy size was associated with several parameters of in-the-moment scores (e.g., means and standard deviations) and participants' active treatment status.

Our results reveal the complex dynamics of in-the-moment symptoms and wellbeing underlying single retrospective scores. In-the-moment assessments offer a new perspective on patients' daily experiences, beyond those provided by traditional retrospective methods. We found that participants with identical retrospective scores often had different averages of in-the-moment symptoms and wellbeing, while others with different retrospective ratings had similar in-the-moment averages. These inconsistencies were most evident for pain, tiredness, feeling energetic, and activity difficulties. Moreover, symptoms and wellbeing often fluctuated substantially within individuals across the 7-day period, with unique patterns, even among those reporting the same retrospective scores. These results suggest that single time-point assessments may overlook meaningful within-person variability, which could be critical for clinical decision-making.[32]

Our findings do indicate that traditional retrospective questionnaire scores are positively correlated with average in-the-moment symptom and wellbeing scores, suggesting that retrospective measures generally reflect patients' average experiences over a week. The findings also support the peak-end rule, indicating that recall is shaped by both peak intensity and recent experiences.[6–8] This was evidenced by the positive correlations between retrospective scores and the maximum and sixth-day mean of in-the-moment scores across all items. For example, participants with a higher maximum and sixth-day mean of in-the-moment pain scores tended to have a higher recalled score compared to participants with lower pain levels. To date, only one health-related study has examined peak-end indicators of in-the-moment scores in relation to 7-day recall scores, reporting similar correlations for fatigue and negative mood in hemodialysis patients.[33] Further research is needed to confirm the rest of our correlational findings.

Interestingly, participants provided on average higher pain and tiredness scores on a retrospective questionnaire compared to their in-the-moment assessments. This aligns with findings from studies in non-oncology populations, such as people with chronic pain

or those undergoing hemodialysis, where retrospective reports of pain and fatigue systematically exceed ESM averages.[33–35] When recalling their experiences, participants may overlook episodes with mild symptoms, instead focusing more on the most intense episodes.[36] Another possibility is that severe symptoms led to skipped ESM assessments, underestimating symptom severity. However, in our study, participants did not report experiencing symptoms as a reason for missing assessments, making this explanation less likely.[16] Notably, our sample did not show the extremity bias that is commonly seen in non-oncology studies, where both positive and negative affect are often overestimated using retrospective assessments compared to in-the-moment assessments.[37] This may be due to our use of single-item affect measures, rather than composite scores of broader affective constructs.[38]

Several factors may contribute to discrepancies between retrospective and in-the-moment assessments, including item score characteristics and individuals' active treatment status. Greater variability of symptoms and wellbeing over time was linked to larger discrepancies. This aligns with findings from populations outside of oncology such as those with chronic fatigue syndrome or chronic pain.[39,40] Surprisingly, participants undergoing active treatment reported higher retrospective than in-the-moment scores, compared to those not undergoing treatment. This could mean that traditional PROMs overestimate symptoms and wellbeing for patients in active treatment or that ESM assessments underestimate them. Because this discrepancy could not be explained by differences in average in-the-moment symptom and wellbeing scores, as these were similar for both groups, this finding could be related to individual differences in coping with illness and treatment. For instance, being in treatment may induce a more negative view on the illness, intensifying the recollection of measured experiences.[36,41] Notably, factors one might expect to influence the discrepancy between the measurement types, such as age, daily smartphone use, and cognitive complaints showed no significant associations. Future research should test formal hypotheses about what drives these discrepancies, guided by theoretical models from cognitive psychology.[42,43] Moreover, further research should look into the clinical meaning of the identified discrepancies, particularly for pain and tiredness, and whether the found predictors are also clinically significant.

Implications for Research and Practice

Researchers and clinicians aiming to understand patients' symptoms and wellbeing should be mindful of people's individual symptom and well-being fluctuations that occur in real-time, which are missed by traditional retrospective measures. Traditional 7-day recall questionnaires in oncology, such as the EORTC QLQ-C30,[4,44] are effective for capturing aggregated data and are well-suited for group-level comparisons with minimal participant

burden. In contrast, ESM provide valuable insights into individual fluctuations in symptoms and wellbeing,[13] but can be more burdensome in general and time-consuming in clinical practice and might miss retrospective contemplation, which in itself is also valuable.[45] Therefore, the choice between these methods will depend on the specific research or clinical goals to be addressed. For example, our previous study showed that ESM was especially insightful for patients with moderate to high symptom burden, as they experienced stronger fluctuations over time.[16]

As there are not many studies comparing ESM and PROMs in oncology, future studies could involve different patient populations, outcome measures (perhaps also including open questions), or recall periods. Moreover, studies could invest in more psychometric evaluations as well as evaluate the clinical utility and significance of both methods.

Strengths and Limitations

We provided unique insights into the complex dynamics of in-the-moment assessments relative to retrospective scores. The ESM-AC questionnaire captured a broad range experiences that were relevant to the target population.[27] However, the study's small sample size likely reduced statistical power for group-level analyses. Also, rescaling the retrospective scores might have introduced artificial discrepancies between the methods, particularly for items or participants with higher severity scores. Nonetheless, the largest discrepancies, namely for pain and tiredness, align with prior research that used identical response scales.[33–35] Additionally, the recall period of the follow-up questionnaire did not fully match the ESM assessment window, but differences in timing did not significantly impact discrepancies. Lastly, symptom severity was relatively low in our sample. Including participants with more severe symptoms may yield different results. Given these limitations, future research should prioritize larger samples with greater diversity in symptom severity and consider using identical response scales for in-the-moment and retrospective assessments.

Conclusion

This study found positive correlations between individuals' retrospective 7-day recall and in-the-moment ESM scores for symptoms and wellbeing, with pain and tiredness showing the largest discrepancies. In-the-moment scores revealed considerable variability between individuals and fluctuations over time, which may be relevant to assess depending on the clinical or research objective.

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Supplementary materials

Supplementary material 1: Study outcomes and measures.
Supplementary material 2: Visual guide for the calculation of discrepancy scores.
Supplementary material 3: Descriptive statistics of all in-the-moment and retrospective scores (N=36).
Supplementary material 4: Layered time series plots of experiences over time, grouped per corresponding retrospective score.
Supplementary material 5: Person means of in-the-moment scores grouped per corresponding retrospective score.
Supplementary material 6: Descriptive statistics of all momentary values for participants that scored the same on retrospective measures.
Supplementary material 7: Kendall's tau correlations between retrospective scores and mean, maximum, and mean of the sixth day of momentary scores, with bootstrapped 95% confidence intervals.
Supplementary material 8: Item-level discrepancy scores, with standard deviation scores and 95% confidence intervals.

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PART IV

CLINICAL UTILITY OF ESM

CHAPTER 8

Oncology Healthcare Professionals' Perspectives on the Clinical Utility of Experience Sampling Methods

Joran Geeraerts, Kim de Nooijer, Lara Pivodic, Lore Decoster, Christel Fontaine, Sofie Joris, Eline Naert, Geert Crombez, Mark De Ridder, Lieve Van den Block

This chapter is based on: Geeraerts, J., de Nooijer, K., Pivodic, L., Decoster, L. Fontaine, C., Joris, S., Naert, E., Crombez, G., De Ridder, M., Van den Block, L. Oncology Healthcare Professionals' Perspectives on the Clinical Utility of Experience Sampling Methods. (submitted at European Journal of Cancer Care, 2025)

Abstract

Background

Experience sampling methods (ESM) use repeated self-report assessments in daily life to assess symptoms and well-being of individuals. While a promising method, their use in oncology clinical practice remains limited and healthcare professionals' perspectives on their clinical utility are underexplored.

Objectives

We aimed to explore healthcare professionals' views on the clinical utility of ESM in oncology clinical practice.

Methods

We conducted semi-structured interviews with a multidisciplinary group of oncology healthcare professionals and used qualitative content analysis to identify key themes and subthemes.

Results

We interviewed 12 healthcare professionals with on average 16.3 (SD=10.0) years of professional experience. Participants reported several benefits of using ESM in practice, such as providing unique insights into the patients' symptom fluctuations, improving patient-professional communication and enabling real-time interventions. They also shared concerns, such as doubts about ESM's added value in practice and for patients themselves (e.g., repeated assessments causing burden). Participants perceived various factors that could impact ESM's implementation in practice, such as questionnaire-related factors (e.g., short questionnaire as facilitator) and practical barriers (e.g., increased workload of screening responses and answering clinical alarms).

Conclusion

Oncology healthcare professionals acknowledge the clinical utility of ESM, particularly for providing insights into patients' needs and allowing real-time interventions. However, future research should address key concerns regarding the methods' feasibility, effectiveness, and practical implementation barriers.

Background

Experience sampling methods (ESM) are a type of diary method that involve completing multiple self-report questionnaires per day throughout daily life, usually via smartphones. ESM can capture unique person-centered information beyond those captured by retrospective methods, such as traditional patient-reported outcome measures.[1] In our previous work, we developed and validated an ESM questionnaire measuring the symptoms and well-being of people with advanced cancer in their daily lives (i.e., the ESM-AC questionnaire).[1,2] In an observational study, we prompted patients multiple times per day over several days to complete this self-report questionnaire.[3] We found ESM to be feasible and acceptable for use in people with advanced cancer.[1,3] We also demonstrated the ability of ESM to provide in-depth understanding of the fluctuations in patients' daily symptoms and well-being, such as for pain and tiredness.[1,3]

Although the use of ESM thus appears promising, its adoption in oncology practice remains limited and its clinical utility, i.e., the relevance and usefulness of this tool as an intervention in patient care,[4] is largely unexplored.[5,6] Nevertheless, studies in other research fields, such as those in mental health research, show increasing interest in ESM as a clinical tool, as they find that ESM have clinical utility by improving patient engagement, empowerment, self-management, goal direction in assessment and care, and shared decision-making.[7] Furthermore, ESM can provide insight into the time and context specificity of symptoms and well-being of patients, which is increasingly recognized as a strength by practitioners and patients in mental health care.[8] These benefits may hold relevance for oncology, where personalized care and symptom tracking are similarly important. However, for successful implementation of ESM into practice, an understanding of healthcare professionals' perspectives on its clinical utility is required.[5] Therefore, the present study explores healthcare professionals' views on the clinical utility of ESM in oncology clinical practice.

Methods

Study design

We conducted a study using qualitative semi-structured interviews with oncology healthcare professionals. The study protocol is published elsewhere.[9] The study was approved by the ethics committees of the University Hospitals of Brussels and Ghent. This report follows the Standards for Reporting Qualitative Research (SRQR) checklist.[10]

Eligibility, setting, and recruitment

Through the authors' professional networks, JG invited healthcare professionals via e-mail to participate in the study. To obtain diverse perspectives, we aimed to include 12 healthcare professionals purposively sampled from various disciplines working at or with the oncology department of University Hospital Brussels (UZ Brussel) in Belgium: two specialists in respiratory oncology, two oncologists specialized in breast cancer, two radiotherapy specialists, two oncology nurses, two onco-psychologists, an oncology social worker, and one physiotherapist.[9] This number was expected to lead to data saturation when identifying perceptions.[11]

Procedures

From June to July 2024, JG conducted all one-to-one interviews at a time and location chosen by participants. Participants first provided informed consent and were introduced to the concept of ESM as a self-report method that uses multiple assessments per day for multiple days with questions that pertain to experiences in the moment (full description in Supplementary Material 1). Following, they reported on their proficiency with computer technology and their experience with electronic tools for patient monitoring, and explored visualizations of ESM data (see 'Instruments' for details). We then explored their perspectives on the clinical utility of ESM in oncology practice. All interviews were audio recorded and transcribed verbatim.

Instruments

The interview guide was based on a survey study on the clinical utility of ESM in mental health practice and assessed participants' perspectives on the following aspects of ESM's clinical utility (Supplementary Material 1):[8]

- The purpose and added value of ESM for healthcare professionals and patients, with additional attention to its ability to generate automated feedback and/or clinical alarms when thresholds are reached; and
- The factors that they expect to influence implementation of ESM in practice; and
- Their preferences regarding the use of ESM in clinical practice (e.g., assessment schedules and which patients or healthcare professionals should use the methods).

The material we presented to participants included visual ESM summaries on symptoms and well-being of our observational ESM study (Supplementary Material 2 for an example).[3] The summaries included responses that patients with stage III/IV lung or stage IV breast cancer (with an Eastern Cooperative Oncology group performance status of ≤2) provided over a 7-day period, in which patients completed up to 10 assessments per day.[3]

We selected responses of patients with low, medium, and high general levels and variability of symptom and well-being.

Analysis

JG analyzed the interviews using qualitative content analysis,[12] performed in the following steps: familiarization with the transcriptions, initial coding, category development to create a coding frame, creation of coding scheme, trial coding to refine the coding frame, final coding, and reporting and interpretation of the resulting coding frame.[12] We conducted all analyses using NVivo V.2. We strengthened the trustworthiness of the findings by using purposive sampling (ensuring relevance and depth of data) and reporting all coded themes for transparency.

Results

Sample characteristics

Twelve healthcare professionals working with cancer patients at University Hospital Brussels participated in the study (Table 1). Most had no experience with ESM or other diary monitoring methods (n=7). Half of participants (n=6) felt "a little handy" in using IT and computers and half (n=6) had no experience with any tools for monitoring patients. All participants were female, had a mean age of 44.3 (SD=10.7) years, with a mean 16.3 (SD=10.0) years of experience in their profession. By the twelfth interview, participants largely reiterated already raised perspectives, with few novel themes emerging (as perceived by the interviewer).

Table 1. Sample characteristics of the interview study (N=12).

Characteristics	N (%) or M (SD)
Profession	
Radiotherapist	2 (17)
Medical oncologist specialized in breast cancer	2 (17)
Medical oncologist specialized in lung cancer	1 (8)
Physiotherapist	1 (8)
Onco-psychologists	2 (17)
Onco-coaches (i.e., specialized oncology nurse)	2 (17)
Breast clinical nurse	1 (8)
Social care nurse	1 (8)
Female	12 (100)
Age in years	44.3 (10.7)

Characteristics	N (%) or M (SD)
Years of experience in current profession	16.3 (10.0)
Skilled in using IT and computers	
Very clumsy	1 (8)
Neutral	5 (42)
A little handy	6 (50)
Experience with tools for monitoring patients	
None	6 (50)
A little	4 (33)
Quite a bit	2 (17)
Experience with ESM or other diary methods	
None	7 (58)
A little	3 (25)
Quite a bit	2 (17)

Identified themes

We reported overarching themes in line with the topics of the interview topic guide. Lower-level themes were inductively coded from data across the whole interview and categorized under the most fitting overarching theme.

Purpose and added value of ESM in practice

Perceived benefits

All participants reported benefits of using ESM in practice (Supplementary Material 3 presents an exhaustive overview of identified subcategories). Most reported that ESM can provide unique insights into patients' needs. Specifically, most suggested ESM could be used to capture fluctuations of experiences and the evolution thereof; some also mentioned ESM can gain insight into symptom associations or triggers (e.g., for pain or anxiety), daily contexts, and symptom prevalence, with minimized recall bias. For example, participants said:

"I think there are lots of fluctuations [in experiences], also for patients... Daily fluctuations, related to their treatment or to their disease in general. That's why I think that very frequent assessments over a short time period can be interesting, to monitor these short-term fluctuations." [P8, onco-psychologist, no experience with diary methods]

"For pain, for example, it is important to have good characterization of the pain during the day, to treat it better." [P1, radiotherapist, no experience with diary methods]

All participants reported at least one benefit of ESM that could improve the efficiency of some aspect of healthcare provision. Most mentioned that ESM could improve communication between the patient and the healthcare professional. For instance, several participants imagined reviewing a visual overview of patients' responses during consultations to guide more focused questions, and one suggested these summaries could be shared in multidisciplinary oncology staff meetings to inform team decisions:

"This [visual ESM summary] already gives you some insight into what that person has in their environment, what they're capable of, or how they're feeling at that moment... during that period. And then you can start asking more focused questions, I think. And you can also see whether they actually need psychological support." [P2, social nurse, no experience with diary methods]

Some participants perceived other benefits that could improve healthcare, including saving time and therefore reducing costs (e.g., by making communication more focused), improving referrals to relevant healthcare professionals (e.g., psychologists), registering and visualizing symptoms and well-being, and signaling the need for care adaptations:

"Identifying which patients have those needs [that can be addressed with physiotherapy] and should be sent to us. Right now, it just depends on the referrer—who they see, and whether that person decides to refer them or not. And if we had something like that [an ESM monitoring system]—just to imagine an ideal world—where all patients fill this out. And [if] that part on physical functioning and symptoms is slightly expanded, more in the direction of physio[therapy]... then we could say, for example, from a certain score—a cut-off point—that they should be referred. That would also save time, because you can't ask too much of the referring physicians either. But if they come in for a consult and see that this or that is red or orange, or shows that score, then we just schedule them an appointment with the physiotherapist." [P7, physiotherapist, no experience with diary methods]

Most participants also reported patient-centered benefits, with most pertaining to improving self-insight and the patient's sense of control. This self-insight could then lead to greater comfort in life:

"So, if you set aside all the practical difficulties and so on, and you ask the patient to start recording certain complaints or symptoms, then the intention is to help them gain an overview. And by gaining that overview, they may also gain control over [symptom or

negative feeling] triggers, control over the consequences, and be able to anticipate situations that might otherwise lead to a different outcome. Which, in turn, could actually lead to greater comfort in their life." [P6, onco-psychologist, quite a bit of experience with diary methods]

Other patient-centered benefits that some perceived were promoting a sense of being cared for, increasing self-empowerment, and being fun to use for self-monitoring, such as when monitoring improvements in symptoms or well-being. For instance:

"Yes, I think it's nice for them [patients] too, to get that kind of overview. I mean, there are many patients who like being involved and thinking along in their care process, and I think this can be a good feedback moment for them. I also think it's nice that they've seen it themselves beforehand, before they come to us—rather than us putting it in front of them in a somewhat paternalistic way. I just think it's enjoyable for them." [P4, oncologist, some experience with diary methods]

All participants perceived at least one benefit that was related to supporting proactive holistic care. Specifically, most mentioned that ESM can signal care needs. Other benefits included the ability to monitor patients at home, promote balanced living through an overview of daily activities such as household tasks and social interactions, and enable more timely treatments and interventions.

"I think this can be really valuable for people who are in the middle of treatment […]. That allows for quick intervention, for example. There are many patients who don't start anti-nausea medication right away, then become extremely nauseous, which has a big impact on their quality of life at that moment. If we can intervene early, we can really reduce the daily burden for that patient and make the treatment process a bit more tolerable." [P8, onco-psychologist, no experience with diary methods]

Concerns

Participants had several concerns regarding the use of ESM in oncology practice. Some suggested ESM may lack added value compared to usual care. For instance, some believed that healthcare professionals can already ask the relevant questions during consultations: *"When you talk with your patient, all of those things [patient needs that ESM can identify] usually come up. Or yes, I think if you show that you're willing to listen to your patient, then those things naturally surface—provided, of course, that you're attentive to them and ask about them. So in that sense, I find it [ESM] less relevant for myself." [P12, onco-coach, a little experience with diary methods]*

Another argued that patient-reported outcome measure (PROM) use does not extend life expectancy and therefore such outcomes cannot be expected from ESM. Some noted that referrals to relevant services are already being suggested. Moreover, one stated the effectiveness of ESM in improving patient outcomes should be evaluated before using it in practice:

"Yes, I think… if you have something like this [ESM tool], you first need to see whether it actually achieves its goal. Because right now, it's just a little project. We haven't tried it yet. Nothing has been done with it so far. So I can't say whether it will add value or not. That all still needs to be evaluated, of course." [P12, onco-coach, a little experience with diary methods]

Some participants mentioned concerns related to communication between the patient and healthcare professional. They mentioned that discussing the visual summary with the patient could be too formal and time intensive, and that there might be less human contact and direct communication between the patient and the healthcare professional:

"But I'm also very much in favor of personal contact. So if I see that someone scores high on pain or nausea, then I really follow that up closely myself. I'll call those patients every two days until they actually tell me, 'It's better now, the medication is working.' I still strongly believe in continuing that personal follow-up rather than, for example, relying on an automatic alert that goes off and then gives advice. I also notice that patients really appreciate that." [P10, onco-coach, a little experience with diary methods]

Others stated ESM could miss relatives' perspectives and the feedback on patients' decline requires supportive framing:

"The decline. I... yeah. Well, I think that can be quite heavy if there's no [supportive] framework around it. So it's good if it's discussed during a consultation, but I wouldn't do it like—like the way we get that weekly report on our phones: 'You've spent this many hours on your phone this week.' I wouldn't present it like that to patients. […] I think it needs to be framed properly." [P11, radiotherapist, no experience with diary methods]

Most participants noted measurement-related concerns with ESM, most relating to the risk of biases in responding (e.g., underreporting symptoms due to avoidant coping style or not wishing to discuss symptoms) and differences in the interpretation of items measuring fatigue, anxiety, and restlessness. Some mentioned challenges such as interpretation of responses requiring follow-up questions or explanations. Several noted ESM captures

experiences that may not require clinical support, particularly when they are transient in nature:

"I mean… everyone feels a bit off at some point during the day—more tired, or something like that… it doesn't always have to mean there's an immediate need to intervene. […] In principle, you could ask it twice a day—three times at most—but does that really add value? I'm not sure. […] Say it's bad in the morning but improves by the evening—then it's something transient, and in that case, we wouldn't need to intervene anyway, so to speak." [P3, oncologist, no experience with diary methods]

Many participants had some concerns related to the patient population. Most stated ESM could lead to negative patient experiences such as burden or confrontation with decline:

"It can be quite confronting, you know, when you suddenly start seeing all those red colors. Imagine someone who checks in every week, like, 'Let me see how my week went,' and for the past two or three weeks everything was green, and then suddenly they see [that this week is going worse]... […] *you have to be careful with that sometimes." [P3, oncologist, no experience with diary methods]*

Other concerns included requiring too much digital skill for some patients, sufficient energy levels to complete the multiple assessments, and willingness of patients to receive support for the monitoring to be useful:

"Of course, there will always be people who won't accept that kind of support—because everyone is different (laughs). […] Sometimes you have patients who need help but don't want it, because they won't accept someone coming into their home, for example. So yes, you can offer personalized feedback, and that's a good thing. But I definitely wouldn't say they'll automatically accept it. Still, at least you've done what you could to help the patient, and it does provide better support overall." [P2, social nurse, no experience with diary methods]

Supportive features: automated feedback and clinical alarms

The interview guide provided additional attention to the added value of the use of ESM of automated feedback and clinical alarms as supportive features of ESM. We therefore report participants perceptions regarding these features, including perceived benefits and concerns, separate from participants' views of ESM in general.

When discussing the specific functionality of ESM to generate automated feedback that could be presented to the patient, some participants suggested patients should receive automated advice directly, containing the suggestion to contact hospital staff or schedule

an appointment, a question if they require help, a visual overview of what the patient experienced, or a link to informational modules. According to some, ESM could thus serve as a reminder of self-management information and as facilitator for timely interventions:

"The personalized feedback… When we [the patient and clinician] are facing a specific problem, then they also immediately get that support."[P2, social nurse, no experience with diary methods]

However, several participants had concerns about automated feedback, including that they still preferred patients to call their healthcare providers to get help if needed, the limitations of general health advice, and requiring (available) staff to answer patients' calls. One stated advice could possibly worsen patients' anxiety:

"That people who are already anxious might start searching even more and end up getting even more entangled. If they get a notification on their phone — 'Ah, you are feeling unwell because of... try this or try that' — then sometimes they go on to Google it further, and then it becomes 'Doctor Google.' And it's a pity that people might become even more unsettled because of that. I would really find that unfortunate." [P6, onco-psychologist, quite a bit of experience with diary methods]

When discussing the generation of clinical alarms through completed ESM assessments, several participants saw clinical alarms as signals to the healthcare professional when patient symptoms or concerns reach a threshold. Either right before a hospital appointment or right after every assessment as a form of active home monitoring. Some saw benefits of clinical alarms, including the ability to detect new symptoms, increased accessibility of help, improved patient communication, and potential time savings. Several mentioned the ability of alarms to facilitate timely interventions:

"Yes, I think it applies to... well, that's the idea behind it. Well, that's the purpose of the questionnaire — that when they reach a certain cutoff, they receive a text message like: 'Hey, is there a problem? Can we do something about it?' […] that you can intervene immediately, that's the goal." [P5, oncologist, quite a bit of experience with diary methods]

However, several participants shared their concerns related to clinical alarms, including difficulties of IT staff to implement this system, requiring the determination of thresholds for when alarms should be triggered, requiring time, signaled needs often requiring clarification first, unavailable staff during out of office hours, availability of patients after the healthcare professional was alerted, and some alarms requiring no action. Additionally, some expected patients should and will call when they experience complaints that require support, making alerts unnecessary:

"[…] usually people will call themselves, right? Or if it's something serious, they will call anyway, right? I don't think they would really wait for the [ESM] questionnaire to report something like that." [P9, breast clinic nurse, no experience with diary methods]

Factors influencing implementation in clinical practice

Factors perceived to influence ESM's implementation in practice were related to the questionnaire, the use by healthcare professionals, practical barriers, and patients themselves. Questionnaire-related facilitators included having alternative questionnaire versions adapted to specific patient groups, same content across repeated questionnaires to increase completion speed, and having a short and simple questionnaire. One participant mentioned false (clinical) alarms could be reduced by asking patients if they have already taken pain medication or if they require support:

"To ease the workload... I mean... everyone feels a bit off at some point during the day. Or a bit more tired, or… you know… it doesn't always have to mean there's an immediate need for intervention. So yes, maybe that's also a question that should be included: 'Do you feel the need for help or support?' So that the system only triggers an alert when the answer is 'yes'." [P3, oncologist, no experience with diary methods]

Some mentioned the implementation of ESM would likely be successful because previous similar projects appeared feasible (e.g., implementation of routine PROMs).

Most participants perceived facilitators related to healthcare professional use. Most mentioned ESM and its visualizations should have accessible integration into the electronic health record, while also questioning whether this would be feasible. Other facilitators included having visualizations that are quick and easy to use for healthcare professionals and information that is actionable.

Many participants perceived practical barriers regarding the need for quick interventions, limited time availability, ESM requiring resources and adding workload. Nevertheless, one noted that healthcare professionals are flexible in how much time they allocate to the discussion of the patients' results, depending on whether they find it effective for the current patient. Moreover, two stated having appointed staff to first screen the responses could help:

"Maybe they [appointed staff] could already identify the more anxious ones [patients], and then refer them to us. So that we know: 'okay, for this patient, let's make some extra time available'. That way, they could already do a kind of pre-selection. Not that we ignore the patients we don't need to worry about, but for those they're unsure about, we could then,

for example, leave more space in the next consultation. I think that could be a good filtering system." [P4, oncologist, some experience with diary methods]

Another participant stated getting all team members on board will be a challenge, but necessary, and shared her own lack of digital skills was a barrier to being interested in using ESM.

Most participants perceived some facilitators for patients, including providing patients with training in using the questionnaire and having a user-friendly design that is usable across all ages. Several stated that responsibilities and expectations regarding the use of ESM should be clearly communicated:

"When it comes to responsibility... if a patient comes to us with many complaints, it must be clear what their expectations are. Do they want help? And to what extent can we actually offer that? It cannot be expected that this [ESM tool and summary of needs] will simply be handed over to a healthcare provider who then has to take on and resolve everything. That expectation should not be created—because that is not possible. I think it should rather be introduced as a tool to open up and facilitate communication, not as some kind of medical miracle solution." [P8, onco-psychologist, no experience with diary methods]

Methodological and practical preferences regarding the use of ESM in clinical practice

Preferences for monitoring periods ranged from 5 days to the entire disease trajectory, with several participants stating monitoring patients for one week is short. While some suggested adapting the period to the treatment at hand, most favored shorter periods, repeated after some weeks or months:

"That [following patients throughout their treatment trajectory] is difficult too, isn't it? Because the treatment also takes a while. And [following patients for] six days, well, that's just one moment—like, it's one week. But maybe you should repeat that again two months later, do another week, so you can compare [how the patient felt then versus later]." [P9, nurse, no experience with diary methods]

Regarding the frequency of daily assessments, preferences varied from less than daily assessments to 10 times per day, with most stating that 10 times per day was excessive and preferring between 3 to 5 assessments per day. Some stated that assessment frequency should be based on evidence of what's feasible and some items should be presented less frequently (e.g., feeling lonely):

"Yes, I think you should talk to the patients who've done it [ESM monitoring], to understand how they experienced it and what they think about it. […] So yes, you'd have to test how feasible that is." [P11, radiotherapist, no experience with diary methods]

Most participants found a 3-to-4-minute completion time acceptable, while others suggested keeping the questionnaire between 10 to 15 items or under 5 minutes.

Participants suggested several optimal target populations for the methods, categorized by patient, disease, and treatment characteristics. For instance, some participants expected benefits for less communicative patients, patients during active treatment or when treatment changes, and those who are less frequently seen by healthcare professionals. Notably, some preferred the use of the methods among people with chronic, metastatic cancer or others receiving palliative care, while other participants mentioned to be cautious for these groups:

"People can remain in a palliative setting for a long time. But I still hold the view that, in that context, comfort should be the priority and patients shouldn't have to think about filling out questionnaires. I do believe that some form of support is very important in a palliative care trajectory, but I definitely wouldn't want to expect patients to still complete questionnaires at that stage" [P10, onco-coach, some experience with diary methods]

Participants highlighted many different professionals treating oncology patients that could use ESM. The most recurring suggested users were onco-coaches as they can refer patients to the right professionals based on the ESM results and are seen as central in the multidisciplinary care team and approachable for the patient. Nevertheless, their time availability was questioned and the two interviewed onco-coaches preferred their traditional ways of working. It was also suggested that oncology physicians could intervene the physical complaints picked up by the ESM and onco-psychologists could receive referrals when psychological needs are signaled.

Discussion

In this interview study, healthcare professionals expressed several benefits of using ESM in oncology practice, such as providing unique insights into the patients' needs, improving the efficiency of healthcare (e.g., by making communication more focused), providing benefits for patients (e.g., improving sense of control), and supporting proactive holistic care (e.g., enabling timely interventions). Key features, such as automated feedback and clinical alerts, could support the use of ESM in practice. However, concerns were raised regarding ESM's added value in practice, impact on the patient-professional encounter (e.g., being too time intensive), self-report measurement issues (e.g., response biases),

and patients themselves (e.g., repeated assessments causing burden). Various factors were thought to hinder or facilitate ESM's implementation in practice and participants had widely differing preferences regarding ESM's methodological features. For example, regarding the optimal monitoring period and target users, including how those users should use the methods.

While barriers and concerns regarding ESM should be taken into account, the unique benefits that healthcare professionals perceived do suggest that ESM can be a clinically useful tool in oncology. At the foundation of ESM's utility is its ability to provide detailed insights into clinically relevant experiences of patients over time and the triggers thereof. Participants suggested such detailed insights could allow for better understanding and treatment of important symptoms, such as pain. This corroborates our previous research with people with advanced cancer, which showed that symptoms and well-being fluctuate considerably in ways that are likely clinically valuable but go undetected by traditional assessment methods.[3] Using ESM to gain these insights might be most relevant for patients who experience moderate to high severity symptoms as their symptoms show stronger fluctuations over time.[3] Research also shows that ESM seem particularly promising for patients with chronic problems that are hard to treat, to gain a better understanding of the problem at hand.[6,13] Another strength of ESM that was suggested by many participants was its ability for real-time monitoring which could lead to timely interventions, such as when using clinical alarms and/or automated feedback. This finding aligns with the positive findings of studies on home-based symptom monitoring in oncology and ecological momentary interventions in mental health care in improving patient outcomes[14–17]. In this study, such monitoring appeared to be most preferred during treatment periods, when the detection of actionable toxicities is crucial. Notably, in addition to benefits unique to ESM, participants also perceived benefits that overlap with those from routine PROM research in oncology.[18,19] For example, participants thought that ESM could make patient-professional communication more focused and improve referrals to relevant healthcare services. For such benefits, less burdensome tools like routine PROMs may thus be more practical.

Participants did raise important concerns about the clinical relevance and burden of ESM. Yet, several of these can be reconsidered in light of evidence. Some participants questioned the clinical relevance of capturing transient experiences which do not always require immediate intervention, such as tiredness. While in line with broader concerns about triggering unnecessary clinical interventions through capturing short-lived fluctuations,[20] both participants' comments and prior research indicate that the repeated assessments of certain transient experiences can be valuable for better understanding symptoms or other experiences. For example, when the goal is to optimize the medication schedule to treat pain or to identify personal symptom triggers of chronic cancer-related fatigue, it is

essential to repeatedly assess the symptoms to characterize their trajectories and determinants over time.[6,7] Moreover, when using clinical alarms, more frequent assessments can enable more timely interventions, but system responsiveness must be carefully managed to avoid overburdening healthcare services.[15] For example, by balancing the sensitivity and specificity of detecting symptoms that require intervention. Additionally, as often reported in ESM research,[7,21] several participants were concerned with patient burden from repeated assessments. Positively, studies in oncology settings increasingly show that ESM is generally feasible and minimally burdensome within periods of one to three weeks.[1,3,5,22] Yet, it remains unclear whether longer, measurement burst designs, preferred by most healthcare professionals, are equally feasible in practice.

Participants also mentioned practical and organizational barriers to implementing ESM in routine care, many of which reflect challenges observed with other symptom monitoring tools.[18,23] For instance, while many participants believed ESM could save time by making communication more focused, several mentioned that an ESM system could bring an added workload and time demands (e.g., by having to discuss the summary or having to answer clinical alarms). To address this, many suggested the ESM system should be user-friendly and quick to use, and some participants suggested assigning dedicated staff to pre-screen responses or using automated thresholds to trigger referrals. Modern monitoring applications often facilitate this by providing clinicians with a dashboard that can filter for key symptoms and further streamline consultations to save time.[24] Importantly, many participants also stated that integration of the ESM system into electronic health records is essential for a good workflow, but participants expected serious challenges with such integration. Despite these anticipated challenges, evidence from routine PROM implementation shows that digital monitoring can be feasible and even save time, such as by reducing emergency visits and long-term workload.[19,25] Researchers should therefore draw from successful digital PROM implementation strategies to help overcome these practical implementation barriers.[18,26,27]

Future studies should investigate the feasibility and acceptability of longer-term ESM protocols in oncology, especially among vulnerable populations such as patients with advanced cancer or those receiving palliative care. Additionally, many healthcare professionals preferred the use of supportive features such as automated feedback, but a lot more work is required to determine key properties of such systems. Specifically, research should determine the optimal content and format of visual or written automated feedback, as well as the thresholds for when this feedback or clinical alarms should be triggered. When it comes to who should use the tool, most participants preferred having a central person, such as onco-coaches, to monitor alarms or flagged patient needs and coordinate referrals. However, there was notable skepticism regarding the use of self-

report tools among the onco-coaches in the recommended roles. Initiating small-scale implementation studies to generate evidence on the effectiveness of ESM to improve patient outcomes may ultimately help reduce this skepticism and support its implementation. Importantly, further research is also needed to determine when the added temporal detail and insights into symptom triggers of ESM offer clinical benefits over routine use of traditional PROMs that use less frequent assessments.[18,19]

This was the first study to explore healthcare professionals views on the clinical utility of ESM in oncology, providing novel and practical insights into how ESM can be used in oncology clinical practice. By reporting on participants' concerns and suggested barriers for implementation, we provided a comprehensive first step towards effectively leveraging the potential benefits of ESM in this setting. By providing participants with visual examples of real ESM responses, we likely enriched the discussions. However, several limitations should be noted. First, the interviews were conducted in a small sample of all-female healthcare professionals from a single hospital, where work culture and limited experience with monitoring tools may have influenced perspectives. Second, to keep the study materials intuitive for the participants, we only provided participants with examples of symptom and well-being time series graphs and pie charts of the daily contexts of patients. Providing participants with concrete examples of how ESM uncover associations between symptoms, well-being, and contexts could have encouraged richer discussions on this topic, which is one of the core theoretical strengths of ESM. Moreover, in this study we presented participants with paper reports, but contemporary technology allows for digital dashboards which could provide more information. Third, including more strategies than purposive sampling and comprehensive reporting of findings, such as member checking or formally tracking data saturation, could have further strengthened the trustworthiness of findings.

Conclusion

Healthcare professionals found that ESM can be a clinically useful tool in oncology, particularly for providing unique insights in patients' needs and enabling timely interventions. Future research should focus on addressing shared concerns to optimize the integration of ESM, ensuring its feasibility, effectiveness, and alignment with clinical needs.

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Supplementary materials

Supplementary Material 1. Interview guide.
Supplementary Material 2. Visual feedback provided during the interviews (English translation, some formatting has changed in translation process).
Supplementary Material 3. Categories of oncology healthcare professionals' perspectives on the clinical utility of experience sampling methods in oncology.

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PART V

GENERAL DISCUSSION

Chapter 9

General discussion

This general discussion includes a summary of the main findings of the studies included in this dissertation, a discussion of the methodological strengths and limitations of their study designs, a discussion of the most important findings of this dissertation, and, finally, recommendations for research and implications for practice and policy.

In this dissertation, we conducted the adaptation of experience sampling methods (ESM) for people with advanced breast or lung cancer for measuring in-the-moment symptoms and well-being in daily life and the variation of these experiences within and across persons (**Aim 1**). We also evaluated the feasibility, acceptability, and ability of ESM to capture symptom and well-being fluctuations in people with advanced cancer (**Aim 2**) and its clinical utility for oncological clinical practice (**Aim 3**).

Summary of the main findings

Aim 1: To inform the adaptation of ESM for people with advanced breast or lung cancer and develop a questionnaire for measuring their in-the-moment symptoms and well-being in daily life, and the variation of experiences within and between people.

In **Chapter 2**,[1] we systematically reviewed the international literature of studies that had previously used intensive longitudinal methods with daily electronic assessments among people with breast or lung cancer. Specifically, we described to what extent the methods were used, the used methodologies, associated outcomes, and factors influencing their implementation. We searched three electronic databases up to January 2024 and included 52 articles reporting on 41 studies. The aims and the methodologies of the included studies varied widely, but most studies mainly focused on measuring physical and psychological symptoms, such as pain, anxiety, and depression. Questionnaire completion and attrition rates seemed to indicate positive feasibility and acceptability of the methods in most studies, although complete methodological reporting was often lacking. We identified factors that could influence implementation of the methods in research and practice, which we linked to both the patient and the methodology. Importantly, only few studies specifically used intensive longitudinal methods among people with advanced cancer and studies used assessment schedules with a low number of assessments per day. With most studies employing 1 to 2 assessments per day.

In **Chapter 3**,[2] we described the development, content-validation, and optimization of the Experience Sampling Methods for People Living with Advanced Cancer (ESM-AC) questionnaire in a three-round mixed methods study. The study included semi-structured interviews with 43 people with stage IV breast cancer or stage III to IV lung cancer and 8 oncology healthcare professionals. Following the first round, we divided an initial item set into a core set of 46 items that was to be used by all patients and a supplementary set of 38 items which patients could optionally select items to personalize the questionnaire. The items covered physical, psychological, social, spiritual-existential, and global well-being domains and concurrent contexts in which these experiences occur. We categorized items

to be assessed multiple times per day as momentary items (e.g., "At this moment, I feel tired"), once per day in the morning (e.g., "Last night, I slept well"), or once per day in the evening (e.g., "Today, I felt hopeful"). In the second round, we improved the comprehensibility of the items. In the third round, we used participants' evaluations to optimize the questionnaire items, the digital app, and its onboarding manual. This resulted in the ESM-AC questionnaire, which comprised a digital core questionnaire containing 31 momentary items, 2 morning items, and 7 evening items and a supplementary set containing 39 items. Participants largely rated the digital questionnaire as "easy to use," with an average score of 4.5 (SD = 0.5) on a scale from 1 ("completely disagree") to 5 ("completely agree").

Aim 2: To evaluate the feasibility, acceptability, and ability of ESM to capture fluctuations in the symptoms and well-being of people with advanced breast or lung cancer in daily life.

In **Chapter 4**,[3] we described the protocol for the studies that addressed both the second and the third aim of this dissertation. In the studies, we aimed to use and evaluate ESM in a small pilot study followed by an observational study with a larger sample, to investigate the daily experiences of people with advanced breast or lung cancer. We planned for participants to complete the digital ESM-AC questionnaire 10 times per day for 6 full days. Furthermore, we planned to investigate fluctuations and temporal relations among measured experiences and context, and to evaluate the feasibility and the acceptability of ESM. The protocol also describes the plan to evaluate the clinical utility of ESM in interviews with oncology healthcare professionals.

In **Chapter 5**,[4] we assessed the preliminary feasibility and acceptability of using the novel ESM-AC questionnaire in an intensive ESM protocol in a small pilot study. In this study, 12 people, purposively sampled across people with stage IV breast or stage III or IV lung cancer and across those below and above the age of 70 years, completed up to 10 ESM-AC assessments per day for 6 consecutive days and shared their experiences with the study during an interview at follow-up. Our findings showed that the methods were feasible and acceptable for people with advanced cancer in our sample, with both younger and older participants completing enough assessments for analysis and generally no burden caused by methods. One of the 12 participants dropped out due to irritation and tiredness. We found considerable variability in most of the measured experiences, which highlighted the relevance of the high-intensity assessment schedule of the used ESM protocol and showed the added value that ESM has over traditional retrospective assessments.

In **Chapter 6**,[5] we evaluated the feasibility and acceptability of ESM for people with advanced breast or lung cancer, and its potential to uncover moment-to-moment fluctuations in symptoms and well-being. Participants were purposively sampled across people with stage IV breast or stage III to IV lung cancer and across those below and above the age of 70 years. Forty of 79 (50.6%) invited persons consented to participate. We found that participants validly completed 71% of scheduled ESM assessments and had positive experiences, indicating low burden, high ease-of-use and instruction clarity, and minimal measurement reactivity. ESM captured within-person fluctuations of symptoms and well-being, particularly for participants with higher symptom intensity. We observed the greatest fluctuations across days for tiredness, feeling relaxed, and activity limitations. We concluded that high-intensity ESM in a one-week assessment period proved feasible and acceptable for use by people with advanced cancer, effectively capturing individuals' unique symptom and well-being fluctuations in daily life. Our findings give credibility to ESM as a highly promising avenue to enhance personalized care and improve quality of life by revealing the mechanisms behind individuals' fluctuations.

In **Chapter 7**,[6] we compared in-the-moment ESM responses with 7-day recall assessments of symptoms and well-being among people with advanced breast or lung cancer and explored factors associated with discrepancies between the measurement types. This study used data gathered in the observational ESM study described in Chapter 6,[5] of which we included 1676 completed assessments of 36 participants in the analyses. Using visualizations and correlations, we found that higher in-the-moment scores were associated with higher retrospective scores (correlations ranged between .24 and .70). However, participants with identical scores on the retrospective questionnaire often had different means and fluctuation patterns of their in-the-moment scores. We observed the largest discrepancies between in-the-moment and retrospectives scores for pain (*Mdiff*=-13.2) and tiredness (*Mdiff*=-12.4) on 0-100 scales. Several parameters of in-the-moment scores (e.g., standard deviation over time (B=1.08, p<0.001)) and participants' active treatment status (B=5.89, p=.010) were associated with the discrepancies between the measurement types. We concluded that individuals' recalled symptoms and well-being generally correlated with their in-the-moment symptoms and well-being over one week. However, given the considerable differences of in-the-moment scores between individuals and their fluctuations over time, ESM may capture clinically relevant individual differences that are missed with traditional retrospective measures.

Aim 3: To evaluate the clinical utility of ESM in oncology clinical practice.

In **Chapter 8**,[7] we explored healthcare professionals' views on the use of ESM in oncology clinical practice. We included a multidisciplinary mix of 12 healthcare professionals,

including onco-psychologists, oncologists, and onco-coaches. Professionals perceived benefits of using ESM in oncology practice, such as providing unique insights into patients' needs, making communicating between the patient and the healthcare professional more focused and enabling real-time interventions through the use of clinical alarms and automated feedback. However, they also shared a range of concerns regarding the use of ESM, including its questionable added value, problems related to self-report questionnaires, and possible burden for patients due to the repeated assessments. Professionals also perceived various factors that could impact ESM's implementation in practice, such as practical barriers (e.g., increased workload of screening responses and answering clinical alarms). Additionally, they had widely differing preferences regarding ESM's practical application, such as for the optimal monitoring period and target users. We concluded that while ESM can be a clinically useful tool in oncology, future work should first address the important concerns and factors that might hinder its implementation in practice. Moreover, many of the reported barriers and concerns overlap with those reported in research using routine patient-reported outcome measures (PROMs). Therefore, to overcome these barriers, researchers could look to studies that have successfully implemented routine PROMs into clinical practice.

Strengths and limitations

Overarching strengths and limitations

The research presented in this dissertation was devoted to uncovering the potential of ESM for understanding symptoms and well-being of people living with advanced breast or lung cancer. To comprehensively assess this potential, we used multiple study designs and research methods, including multiple rounds of semi-structured interviews, and both traditional retrospective and in-the-moment ESM questionnaires. The mixed-methods approach contributed to the depth and richness of the findings presented in this dissertation. Furthermore, our research approach was characterized by a strong commitment to actively involve both people living with advanced cancer and oncology healthcare professionals, ensuring the integration of their perspectives in this research. We also included equally sized groups of people with cancer that were aged below and above 70 years, to provide representation of typically underrepresented older adults in cancer research.

Two overarching limitations should be noted. First, in our studies, we included people with advanced cancer that had relatively high functional status, meaning they were often treated in outpatient care, capable of most to all activities of daily living, and not confined to a bed or chair for most of their waking hours. Our results may therefore not generalize

well to people with advanced cancer that have lower functional performance status. Second, it is possible that patients treated in university hospitals differ systematically from those in non-university settings (e.g., in disease complexity, socio-demographic characteristics, or familiarity with research participation). Recruiting solely at university hospitals could thus have led to selection bias and overrepresentation of certain patient profiles.

Scoping review of intensive longitudinal methods for people with breast or lung cancer

We conducted a scoping review of research that reported on the use of digital intensive longitudinal methods in people with breast or lung cancer (**Chapter 2**).[1] A major strength of this review was the comprehensiveness of the overview that it provided. This was achieved by using a broad search strategy with an exhaustive search string in three online databases. Moreover, we included studies that assessed participants daily or multiple times per day, as information on the use of daily diaries (that typically ask for one assessment per day) could be informative for studies on ESM that typically utilize multiple assessments per day.

The study was limited in that it could have missed some literature that reported on assessment methods that used other terms than those used in the search strategy. However, this seems unlikely, given the exhaustiveness of our search string and the fact that we included studies that other similar reviews had missed.[8,9] Additionally, a second reviewer only checked 10% of the data extraction and none of the updated search, which could have overlooked inaccuracies in data extraction. However, the reviewers had regular discussions while developing and extracting the data and there were no disagreements in the 10% of data that was compared, thus limiting the likelihood of inaccuracies.

Questionnaire development through interviews with patients and healthcare professionals

We conducted three rounds of semi-structured interviews with people living with advanced breast or lung cancer and one round of interviews with healthcare professionals to develop, content-validate, and optimize the ESM-AC questionnaire (**Chapter 3**).[2] This study was among the first to answer recent calls for content-validation of questionnaires to be used in ESM research.[9,10] Consequently, the ESM-AC questionnaire is the first ESM questionnaire in oncology that was rigorously developed to ensure its content validity, following Consensus-Based Standards for the Selection of Health Measurement Instruments (COSMIN) methodology and the European Organization for Research and Treatment of

Cancer (EORTC) guidelines for module development.[1,9,11,12] The development and testing of the questionnaire involved close collaboration with people with cancer and healthcare professionals, which ensured its relevance for the target population. The relevance was further ensured by adapting items from existing validated PROMs and including a free-text questionnaire item that future participants can use to report experiences not included in the ESM-AC questionnaire.[13–15]

The study also had some limitations. First, the oldest participant in the last round of interviews was 78, limiting our insight into the usability of the digital ESM-AC questionnaire for older people. Second, we did not record whether patients were actively receiving treatment in the period in which the interview was conducted. Therefore, we lack this information for contextualizing our findings. Third, as we decided after the first round to include evening assessments items that were previously excluded due to their low expected within-day variability, we could not assess their relative importance due to time constraints in the second round's interviews. Fourth, although the interviewer perceived saturation of novel themes to be included in the questionnaire, formally tracking saturation using established qualitative methods would strengthen the methodological robustness of the content-validation findings.

Pilot and observational ESM study

We conducted a pilot ESM study in a small sample of people with advanced breast or lung cancer and repeated the design in an observational ESM study in a larger sample to evaluate the feasibility, acceptability, and ability of ESM to assess symptoms and well-being and its fluctuations of people with advanced cancer in daily life (**Chapters 4 to 7**).[3–6] A strength of these studies was the combination of ESM design with a follow-up interview session that collected both quantitative and qualitative data on participants' experiences with the methods. Additionally, we used the ESM-AC questionnaire, which we had previously developed, content-validated, and optimized in close consultation with people with advanced cancer and oncology healthcare professionals.[2] In line with ESM research from other fields, the ESM-AC questionnaire also captures everyday contexts, making this dissertation's studies among the first in oncology to assess what situations people with advanced cancer go through in their everyday lives. Additionally, our study was the first study to use a high frequency assessment schedule in people with cancer, which provides a detailed exploration and unique insights into the variability of symptoms and well-being both within and across days, alongside its feasibility and ability to do so. Moreover, we provided unique insights into how repeated in-the-moment assessments of symptoms and well-being captured with ESM relate to those captured by traditional retrospective questionnaires.

Some limitations should be noted. First, we followed participants over a limited period of 6 days, which possibly does not capture a representative range of participants' activities and experiences. Second, we did not purposively sample groups of individuals with different levels of digital skills. Consequently, we observed a high proportion of participants with experience in using smartphone technology in our sample, with some people explicitly declining participation due to having limited smartphone experience. This limits the generalizability of some findings to those with less digital skills. Third, the study required participants to carry an extra smartphone device with them in addition to their own device. This could have led to missing data if participants forgot to take the extra device with them. Fourth, the used ESM-AC questionnaire measures each construct with a single item. This made the questionnaire vulnerable to mistakes in responding. However, discussing visual feedback with participants after the ESM period helped identify and exclude erroneous responses. Fifth, although the 80% completion rate and the high willingness of most participants to participate again suggest genuine positive experiences, the researcher's presence during the follow-up session could have induced socially desirable responses of participants' study experiences.

Additionally, some limitations related specifically to **Chapter 7**,[6] in which we compared in-the-moment ESM responses with 7-day recall assessments of symptoms and well-being. First, as the sample size of the observational ESM study was focused on testing the general feasibility, it limited the statistical power for group-level analyses. Second, the retrospective follow-up questionnaire used a 4-point Likert scale to be consistent with often used measures in oncology, while the in-the-moment assessments used a 0-100 slider scale. Rescaling these scores may have introduced artificial discrepancies between the two methods, particularly for those items or participants with more non-zero severity scores. Nevertheless, the largest discrepancies that we found were for pain and tiredness and closely align with the findings of other studies outside of oncology that compared methods with identical response scales. Third, the follow-up questionnaire was often completed on a different day as the ESM assessments were finished. This means that the 7-day recall period may not have perfectly aligned with the ESM period and its in-the-moment assessments. Nonetheless, we did not find a significant effect of this time difference on the discrepancy between the methods. Fourth, Finally, the average symptom severity of participants was generally low. Including participants with more severe symptoms may change results.

Interviews with healthcare professionals

We conducted semi-structured interviews with healthcare professionals in oncology to explore their views on the clinical utility of ESM in oncology clinical practice (**Chapter 8**).[7]

We were the first to systematically assess and report the perspectives of healthcare professionals regarding this topic and used visual examples provided by real participants of the previous observational ESM study (**Chapter 6**).[5]

Although the findings were rich in content (e.g., we collected a broad range of perceived benefits and concerns), a limitation of the study was that all participants worked in one hospital and had limited experience with using electronic monitoring tools. Future studies could focus on interviewing participants with more monitoring experience to possibly provide even richer and more nuanced insight into what ESM could mean for oncology, which barriers its implementation may encounter, and how to best address them. Another limitation was that we presented examples of ESM responses to the clinicians, which included summaries of ESM data visualized through stacked bar charts, time series graphs, and pie charts. Adding graphs that showed associations among symptoms and contexts, or interactive dashboards, could have led to richer discussions on some of the unique theorized benefits of ESM.

Discussion of the main findings

This section provides an in-depth discussion of the main findings presented in this dissertation, both in relation to each other and the recent scientific literature on this topic.

ESM as a promising research tool in advanced cancer

ESM as feasible, acceptable, and capable tool

The overarching aim of this dissertation was to uncover the potential of ESM for understanding the symptoms and well-being of people with advanced cancer. Important conditions for ESM to effectively enable this potential in advanced cancer are its feasibility, acceptability, and its ability to capture fine-grained symptom and well-being fluctuations in daily life. In this dissertation, we provided positive evidence for all these conditions.

This dissertation demonstrated that ESM was both feasible and acceptable for use by people with advanced cancer. Participants in our high-intensity ESM study completed 80% of the ESM questionnaires and most did not find the repeated ESM assessments burdensome (Chapters 5 and 6).[4,5] Furthermore, the review of intensive longitudinal methods in Chapter 2 showed that studies with lower-intensity designs also appeared feasible.[1] Notably, the reported questionnaire completion rates are comparable to those in healthy populations, extending findings of a recent meta-analysis of ESM studies across research fields that health status is not associated with completion rates.[16]

Several factors could have led to the good completion rates in our studies. Participants were highly motivated to help improve the care for future patients (Chapter 6).[5] Most participants were not professionally active and were at home for a considerable amount of their study time, which may have reduced the likelihood of interruptions when prompted to complete assessments (Chapters 5 and 6).[4,5] Additionally, symptom burden in our sample was relatively low, most participants were highly educated and had confidence in using smartphones, and all received training in using the smartphone device as part of the study (Chapters 5 and 6).[4,5]

The low drop-out rate (i.e., only one participant in each ESM study), the low reported burden, and the high questionnaire completion rates of the observational ESM studies were surprising (Chapters 5 to 6).[4,5] During the development and evaluation of the ESM tool, many healthcare professionals were concerned about repeated self-monitoring being unfeasible or causing burden to populations that already go through difficult periods (Chapter 8).[7] Our data provide an important counterargument to these expectations, as the concerns about burden could lead to considerable gatekeeping for the inclusion of

participants in ESM research in advanced cancer care.[17,18] Additionally, during the development of the ESM-AC questionnaire (before the start of the ESM studies), most participants also expected the 10 assessments per day would be too many (Chapter 3).[2] This discordance between patients' expectations and what they actually experienced when using self-monitoring tools was also reported by a study using a single PROM assessment per day in oncology.[19] It could reflect a broader tendency of people to overestimate the future effort that questionnaire completions will take.

The findings of this dissertation also show that ESM fulfills its potential to capture fine-grained changes in symptoms and well-being during and across days (Chapters 5 to 7).[4–6] Specifically, using a high-intensity ESM protocol, our study was the first to show that clinically relevant symptoms and well-being indicators fluctuate considerably and often change after short time intervals for many of the people with advanced cancer (i.e., notable changes with approximately 1 hour and 15 minutes between assessments; Chapters 5 to 7).[4–6] This finding extends those of the few earlier studies in advanced cancer that used considerably fewer assessments per day.[1,9] For instance, the highest intensity study before those reported in this dissertation was that of Badr et al., who prompted women with stage IV breast cancer 6 times per day, and also found considerable fluctuations over time for pain, tiredness, and mood.[20] We thus added further detail to these change processes and even showed that capturing these processes in greater detail might require more than 10 assessments per day for some patients (Chapter 6).[5] Moreover, this finding aligns with the increasing use of ESM in other physical and mental health fields to study experiences, such as pain, tiredness, mood, and psychopathological symptoms that are increasingly seen as dynamic and interconnected in time.[9,21–25]

Despite the promising aspects of using ESM as a research tool in advanced cancer (Chapter 5 to 7),[4–6] this dissertation also showed that not all patients are eager to participate in ESM studies. This has been identified as a pressing issue for ESM research.[26] For instance, similar to those in other studies in people with breast or lung cancer (Chapter 2),[1] the enrollment rates of our ESM studies were approximately 50%, indicating that half of asked patients did not wish to participate.[4,5] These rates were notably lower than those of our interview studies (72% and 91%).[2] Patients' reasons for non-participation in our ESM studies can largely explain this difference in participation rates. Specifically, some patients were unwilling to participate due to limited smartphone experience, had no time (to participate in a time-intensive study), or thought it would be burdensome. This could have led to a selective filtering of digitally experienced and higher educated individuals observed in Chapter 6.[5] Researchers should thus aim to improve the inclusivity of ESM studies. Nevertheless, it should be anticipated that there will always be individuals who are unwilling or unable to participate. Therefore, work is needed to explore if there are personal

differences between those that participate and those that do not, as it could impact the generalizability of future ESM research.[26]

There are some limits to the generalization of the findings of this dissertation across people with advanced cancer. Our ESM studies did not include participants with low physical functioning status and did not assess symptom burden of those that did not participate.[4,5] It is possible that ESM is less feasible in those with a low physical functioning status and high symptom burden. For instance, research on routine PROMs shows that patients with advanced cancer and worse physical functioning (Karnofski Performance Status < 50) often have lower adherence in self-monitoring protocols.[27] Yet, in a small ESM study across one week that followed fifteen home hospice patients with terminal cancer, Hachizuka et al. did not find a relation between physical functioning and questionnaire completion rates.[28] Moreover, they reported an average questionnaire completion rate of 90% across the sample.[28] However, Hachizuka et al. did not include participants that were completely disabled as operationalized by an ECOG status of 4.[28] For patients with an ECOG score of 4, the feasibility of conducting any form of self-report questionnaire could be severely limited. In these cases, proxy reporting may be the only viable alternative. Additionally, while patients were often willing to help the researcher and future patients (Chapter 6), it is unclear how these enrollment and completion rates generalize to a more clinical context, where patients complete the questionnaires for themselves.[29] In such contexts, patients' perceived benefits, endorsement, and intrinsic motivation of using the methods will likely become even more important.

Careful design decisions precede the use of ESM

Designing an effective ESM study requires a series of deliberate and well-justified decisions, given the many methodological choices available to researchers, as shown in Chapter 2.[1] Each aspect of an ESM protocol, from item selection to sampling frequency and delivery method, can critically influence data quality, questionnaire completion rates, and the validity of findings.[30] In this dissertation, several choices were made to maximize methodological rigor.

An important first step in designing ESM for use in people with advanced cancer was the development and validation of an ESM questionnaire (Chapter 3).[2] In ESM research, it is common for studies to develop their own questionnaires without extensive validation, often modifying items from existing retrospective instruments. However, as Stone et al. recently emphasized, items that are suitable in retrospective contexts may not retain their relevance in momentary assessment.[26] This lack of validation has also led to multiple calls for more content validation of ESM questionnaires.[9,10] Hence, developing a content-valid ESM questionnaire, i.e., a questionnaire that is relevant, comprehensive, and

comprehensible for measuring the concept of interest in the target population,[31] was addressed early in this dissertation's project.

The ESM-AC questionnaire's constructs largely align with most of the traditionally used PROMs in oncology, but uniquely includes items on affect and context.[2] In this way, the content of the ESM-AC questionnaire can be viewed as more holistic in terms of bringing attention to everyday emotions and situations that patients deem relevant and important (Chapter 3).[2] Furthermore, as we created a supplementary item list, the content of the ESM-AC questionnaire can be easily tailored to the individual needs of the specific patient. This is important, as research shows that patients prefer questionnaire content that is tailored to their needs and this can improve response-related outcomes such as adherence to the study.[32] While we focused on gaining a comprehensive list of items that measure symptoms and well-being, there are also other phenomena with clinical relevance that can be measured in daily life to gain an even fuller picture of a patient, such as their thoughts or behaviors.

The development of our ESM-AC questionnaire does contrast with many questionnaires in ESM research (Chapter 2).[1] It was broadly developed to explore how relevant and important symptoms and well-being of people with advanced cancer fluctuate and associate over time, as opposed to testing formal research questions about concrete experiences.[33,34] In this way, our project followed a more bottom-up approach through which the development of the questionnaire influenced which research questions could later be studied, as opposed to a top-down approach in which researchers create a questionnaire in function of a hypothesis that they want to test. This comprehensive bottom-up approach could allow for broader use of the questionnaire in clinical practice, as all the symptoms and well-being included in the questionnaire are relevant and important for most people with breast and lung cancer.

Given that concrete guidelines for questionnaire development based on its content validity did not exist in the context of ESM research, we followed established guidelines for the development and content-validation of traditional PROMs.[11,12] Since our study was one of the first to explicitly report on this development and validation process, it could serve as a 'good practice' example for researchers who wish to do the same.

Beyond questionnaire content, the sampling intensity and study duration were key elements of our ESM design. While most ESM studies in oncology have employed low-intensity designs (likely due to concerns about participant burden; Chapter 2),[1] we used a more intensive assessment schedule for a shorter duration, namely 10 assessments for 6 days. This schedule aligns with a large portion of ESM studies in other fields and allows for the more detailed study of change processes in symptoms and well-being over time.[16,30]

To keep the total time required of the patient approximately the same as lower-intensity designs, we limited the study period to 6 days.[26] Following participants for a longer period, such as 2 to 3 weeks, could introduce a greater variation of daily contexts, such as activities or social company. Yet, in that case, a lower intensity design with less temporal detail would be recommended to minimize participant burden. This was indicated by many participants in Chapter 5 and 6 reporting that 10 assessments was acceptable because they knew that it would end after that 6-day period.[4,5] Both low and high intensity designs thus both appear equally feasible and acceptable in people with cancer, particularly when the intensity of the design is balanced by the length of the assessment period.[30] Furthermore, the above indicates that there is no one-size-fits-all design, and the design should always depend on the research question at hand.[30]

Another important design consideration in ESM research is the choice of device used to administer assessments. We chose to provide participants with a dedicated smartphone device (Motorola E20, approximately €110). The choice for a dedicated smartphone instead of using patients' own phones was based on several reasons: some participants didn't own smartphones, the phone would always have internet connectivity through cellular networks (connectivity is required for receiving assessment prompts in m-Path), and the phone could be preconfigured with the correct settings (e.g., volume on, distracting apps removed). Furthermore, as we had thoroughly tested the usability of the m-Path questionnaire on this specific type of device (Chapter 3 and 5),[2,4] we could ensure a consistent user experience across all participants. Importantly, participants in the studies described in Chapters 5 and 6 did not find carrying an additional device burdensome.[4,5] While smartphones offer greater usability than the more cumbersome personal digital assistants (PDAs) used in early digital ESM research (Chapter 2),[1] emerging technologies such as smartwatches may represent the next step.[35] However, although smartwatches appear promising for simple scale-based input, their small screen size may limit their practicality for ESM studies that require textual responses or use multiple-choice items with many response options.

From research to practice: the clinical utility of ESM in oncology

While the studies in this dissertation predominantly showed that ESM is a promising research tool in advanced cancer, it also sheds light on how ESM can have direct utility in cancer care. Specifically, Chapter 8 identified that ESM has clinical utility in oncology practice through two primary functions: first, as a tool for obtaining more detailed and nuanced insights into patients' problems (on a single case basis); and second, as a foundation for delivering real-time interventions.[7]

Gaining a better understanding of patients' problems

To provide detailed insights into the patients' problems, it was suggested by healthcare professionals in Chapter 8 that ESM could be used to characterize symptom trajectories.[7] For instance, according to the interviewed healthcare professionals, characterizing pain could lead a better understanding thereof and to allow for the optimization of medication schedules (Chapter 8).[7] This suggestion aligns with the view of clinically relevant phenomena as dynamic in nature (Chapters 2 and 5 to 7) and could help to facilitate interventions that are tailored to the patient.[1,4,4–6,9,21–25] Despite this recognized potential, the clinical use of ESM to characterize short-term symptom trajectories has received little to no attention in practice (Chapter 2).[1]

In Chapter 8, healthcare professionals also suggested that ESM could be useful for identifying factors associated with patients' problems.[7] These included factors such as sleep influencing anxiety and tiredness, but also relations such as the influence of certain activities on experienced symptoms.[7] This finding underscores ESM's theoretical strength of uncovering within-person associations between experiences, as highlighted in Chapters 2 and 5.[1,4] Importantly, this finding adds to the relevance of the limited number of oncology ESM studies that use network approaches to uncover associations between clinically relevant experiences[36,37]. While we did not assess for which problems such insights into associations might be most actionable,[7] prior ESM studies in oncology suggest that dynamic, chronic and difficult-to-treat problems may be particularly suitable targets.[36,37]

Notably, as an interviewed healthcare professional mentioned in Chapter 8, the use of symptom monitoring diaries to gain a better understanding of patients' problems is not new in oncology.[7] For instance, for onco-psychologists, pen-and-paper diaries are an established tool in cognitive behavioral therapy[38] and patients often already keep a symptom diary that they discuss with their healthcare professional during consultations.[19] Yet, the integrated use of these methods has seemingly received very little evaluation in research. Implementing more formal research methods such as ESM instead of less structured diaries could allow for more structured data. This structured data could lead to easier scientific evaluation of their effectiveness in improving patient outcomes and could make it easier to identify relevant patterns and gain novel understandings by using visual dashboards.[30,39]

Real-time interventions

As suggested by healthcare professionals in Chapter 8, ESM could enable real-time interventions by integrating supportive features such as clinical alarms and automated feedback.[7] This approach seems promising, with feasibility and effectiveness supported by

evidence identified in our scoping review (Chapter 2),[1] which showed that oncology symptom monitoring systems using twice-daily assessments with alerts and feedback improved pain management, treatment adaptation, and patient–clinician communication.[40–45] Additional support for the use of automated feedback comes from studies into ecological momentary interventions and just-in-time adaptive interventions outside of oncology.[46–50] These have shown usability and effectiveness for improving mental health, health behaviors, and self-management.[48,51–55] Such approaches may thus translate well to oncology, where healthcare professionals recognize the benefits that they can provide (Chapter 8).[7]

Challenges for implementation of ESM in clinical practice

Despite all the benefits that ESM could bring to (advanced) cancer care, the findings of Chapter 8 showed that successful implementation might prove challenging and therefore requires special attention. Similar to research into routine PROMs,[19] an important concern of healthcare professionals was that self-monitoring tools may bring an added workload (Chapter 8).[7] While the clinical use of ESM relying solely on automated feedback with self-management advice can be programmed outside of clinical practice, clinical alarms or feedback with the instruction to contact the hospital indeed require available staff and resources. In those cases, having dedicated staff such as an onco-coach, psychologist, or social worker may be necessary to save time for other medical staff as to not add work on top of their other duties.[56] Yet, having dedicated staff can require considerable resources, which may not be available for all oncology or palliative care departments.[57] For instance, healthcare professionals in Chapter 8 noted that physicians may be less suited to take on this task, given the high financial cost of their time.[7] On top of assigning dedicated staff, there are many other factors required for successful implementation that require resources.[58,59] This includes the integration of an ESM system into established clinical workflows (e.g., having access to the ESM system through the electronic health record) and technology support by IT staff. Given the resources required for the implementation of ESM in practice, providing evidence for its effectiveness in improving patient outcomes, such as symptom management and shared decision-making, will be vital.

Furthermore, not all cancer or palliative care departments may have the right environment for optimally using symptom monitoring tools. As Oldenburger noted in her PROM implementation research, a suitable environment must endorse and be capable of supporting the holistic needs of patients, such as through its work culture, appropriate training in handling needs, and a having multidisciplinary team.[57] This may not be the case for all hospitals.[60]

The relationship between in-the-moment ESM and traditional retrospective PROMs

In oncology, traditional PROMs are typically used to assess symptoms or quality of life either once or at specific intervals, with weeks or months between assessments. In contrast, ESM repeatedly capture in-the-moment data in the natural setting throughout the day. Hence, the two methods measure distinct information (i.e., retrospective vs in-the-moment) and each might have their unique strengths and limitations. As we have shown throughout this dissertation, ESM should be seen as a complementary tool, not as a replacement of traditional PROMs.

Chapter 7 of this dissertation showed that single retrospective PROM assessments often obscure differences in temporal patterns and person-means over a time period (that can be captured with ESM).[6] However, we found that PROMs still approximate the group-level mean that would be measured with ESM (Chapter 7),[6] and hence may be useful when minimizing patient burden is a priority. Additionally, retrospective PROM responses rely on autobiographical episodic memory, which may not necessarily be optimized for accurately remembering information but may serve adaptive functions to guide future behaviours.[61,62] Reflecting on this, Van den Bergh & Walentynowicz (2016) have suggested that the responses to retrospective questionnaires may be more predictive of health-related decisions, treatment adherence and illness behavior than the in-the-moment reports of ESM.[61] Hence, retrospective questionnaires also have unique value over ESM.

Ultimately, the choice between using traditional PROMs or ESM should thus depend on the specific research or clinical question (Chapter 5).[4] If one is interested in gaining insight into general needs (that is influenced by autobiographical episodic memory), less frequent PROM assessments can be ideal and cause less questionnaire burden. Less measurement burden could be preferred in contexts where long term adherence to self-monitoring is important, such as in a clinical setting where patients could benefit from being regularly monitored during treatment and follow-up. Alternatively, if one is interested in the short-term temporal patterns of symptoms and well-being and how these associate amongst each other and with daily life contexts, ESM would be the appropriate method.

Recommendations for research and implications for practice and policy

Reflecting the study's methodological orientation and its primary contribution to fundamental research, this section is mainly focused on presenting concrete recommendations for future research, with some implications for practice and policy. The implications are framed as informed reflections on how the findings may shape or influence clinical practice.

Recommendations for future research

Advance research into symptoms and well-being in advanced cancer and palliative care

Given the significant fluctuations in clinically relevant symptoms and well-being indicators (Chapters 2 and 5 to 7),[1,4–6] an important next step is to determine what drives them. Using ESM to study these drivers or determinants could greatly advance research on the symptoms and well-being of people with advanced cancer (Chapter 5),[4] a research field that has traditionally relied on retrospective measures with limited temporal detail. Concretely, by gaining a better understanding of the determinants of symptoms and well-being indicators, researchers can identify optimal targets for interventions. This new information could aid in the development or updating of guidelines for the treatment and support of symptoms.

Using the data from this dissertation, we will be able to merge the data of the pilot and observational ESM study (Chapter 5 and 6)[4,5] and investigate how the different symptoms and well-being of people with advanced cancer are associated, as well as their associations with daily life contexts. For instance, we will investigate how different activities, social contexts, and locations impact patients' affective well-being (i.e., positive and negative affect) and how experiencing physical symptoms moderates this relationship. Additionally, we will further add to the limited number of ESM studies on cancer-related fatigue by studying its in-the-moment determinants, such as affect, pain, and activities, in daily life.

ESM can also greatly enhance insights gathered in interventional studies. For instance, May et al. note that ESM can be used as an outcome measure in clinical trials to measure changes in pain experiences that are not confounded by changes in beliefs about pain and symptom recollection (i.e., retrospective biases).[23] In the context of early palliative care interventions, others have noted that ESM could aid in determining why some interventions work and others do not, by broadening the scope of research to include affective processes.[63] For example, how quickly affective fluctuations (as captured in Chapters 5

and 6)[4,5] go back to 'normal' levels after negative events could provide insight into patients' well-being and coping processes. Such processes are missed by traditionally relied-upon quality of life and depression measures but, as Ferrer and Padgett (2015) have noted, could partly explain the (in)effectiveness of palliative care interventions.[25,63] Furthermore, repeatedly sampling symptoms introduces new outcomes that can be more informative than the standard mean, such as the proportion of time that a symptom is experienced or not.[64] As such, in pharmacological trials, the temporal knowledge gathered with ESM on the effectiveness and side-effects of an intervention could be used to better inform future patients as they make treatment decisions.[65]

Given that the use of ESM in both oncology and other health research fields is still in an early stage and relies mostly on self-report data (Chapters 2 and 5),[1,4] an important part of gaining a better understanding of symptoms will be to couple the self-report data of ESM with several other modalities. Coupling ESM to biomarkers such as cortisol could provide valuable insights into the physiological processes that underlie symptoms such as pain and fatigue. Additionally, research should further expand the contextualization of relevant ESM outcomes by including active measures such as food diaries or passive measures such as GPS or activity tracking. Importantly, this passive data could also be used to trigger ESM assessments at significant moments that may be of interest, such as when a patient has been sedentary for a long time. This also provides the opportunity to spare participants in moments that matter less for the research question at hand. Adding more open-ended questions will likely be vital in providing richer contextualization.[66]

To determine the most pertinent topics to study with ESM, researchers could look at dynamic problems that are still not optimally addressed in people with advanced cancer, such as pain and fatigue, or emotional problems.[24,25,67–69] For such problems, there might be most room for improvement and there might be considerable in-the-moment determinants that ESM could uncover. Additionally, researchers could collaborate with patients and healthcare professionals to determine what they deem to most important questions.[70]

Conduct implementation studies for ESM in clinical practice

Healthcare professionals interviewed in Chapter 8 recognized the potential of ESM as a tool in oncology for both gaining a better understanding of patient needs and for providing real-time interventions. However, they also mentioned several barriers and concerns regarding the implementation of ESM into practice. Therefore, to move ESM from research into clinical practice, future work should focus on structured development and testing of ESM interventions.

An important first step will be to further involve all stakeholders (including patients and relatives) to identify problems that ESM could help address and start developing the intervention. Furthermore, Chapters 2 and 8 highlight the importance of addressing key implementation questions during the development of the intervention.[1,7] These include determining which patients and needs that ESM will be used for, how to use ESM (e.g., automated feedback or gaining better understanding of needs), the healthcare professionals that will use ESM, the thresholds to use for automated feedback or clinical alarms, and the content to present in automated feedback. Importantly, patients' openness to using ESM as a clinical tool should be explored, as we did not include their views in the exploration of ESM's clinical utility in Chapter 8. Additionally, Chapter 8 showed that, to build support among healthcare professionals and institutions, small-scale effectiveness studies will be essential.[1] These should assess not only symptom improvement but also process-related outcomes, such as impacts on clinical decision-making, patient engagement, and self-management.[29,71]

In addition to broader implementation strategies, attention must be paid to digital inclusivity to ensure that ESM interventions are accessible and usable for all patient groups. In the development and implementation of ESM, the findings of Chapter 6 highlight the importance of ensuring accessibility for older adults and individuals with lower levels of digital literacy.[5] Promoting digital inclusivity may require flexible approaches, such as offering alternative formats like pen-and-paper diaries or adapting response formats (e.g., using Likert scales instead of 0–100 visual analogue scales). However, pen-and-paper methods limit key advantages of digital ESM, such as the ability to provide real-time feedback or trigger automated clinical alerts. To support proper use of the methods, training could place greater emphasis on explaining the response scale and verifying the patient's understanding, for example during a check-up call. It is important to note that such personalized training is likely feasible only in settings with close contact between the patient and the researcher or clinician and may not be scalable to studies or clinical use with larger samples. For broader implementation, future research should explore how to optimize training materials, such as instructional videos or short quizzes, to enhance comprehension and proper use of ESM tools among diverse patient populations.

Continue methodological evaluations of ESM

While the findings of this dissertation provide encouraging evidence for the potential of ESM in both oncology research and practice, considerable methodological gaps remain that need further investigation. The feasibility of measurement burst designs, in which shorter ESM periods are repeated over longer periods of time, is unknown for studies in people with advanced cancer (Chapter 2).[1,9] However, the use of this design could provide

valuable insights into how symptom and well-being dynamics change over longer periods of time, such as during disease or treatment trajectories.

Optimal ESM protocols, e.g., to optimize completion rates and reduce burden, may differ depending on whether they are used for research or clinical purposes. This raises important questions such as: What is the ideal sampling schedule to support the provision of personalized feedback or trigger clinician alarms? Are assessments more feasible and less burdensome when presented on fixed times (compared to random times), and do assessments at fixed times compromise the clinical or scientific value of the data? Future studies should address these questions and consistently follow ESM reporting guidelines to facilitate systematic reviews and meta-analyses (Chapter 2).[72,73]

Given the small samples sizes of ESM research in oncology (Chapter 2),[1] the scalability of ESM remains uncertain. Specifically, it is unclear how feasible ESM is in larger-scale implementations where patients do not receive individual training or support in using the digital diary. Research should explore alternative onboarding strategies that maintain usability without intensive researcher involvement.

Chapters 5 to 7 indicated fluctuations using time series graphs, within-person standard deviations, and intra-class correlation coefficients. Yet, it should be acknowledged that the full range of 0-100 VAS scores may reflect a level of precision that participants cannot reliably provide or interpret differently. Small numerical changes may reflect measurement noise rather than meaningful variations in experiences. Positively, a recent ESM study in a student population compared a seven-point Likert scale with a VAS for affective experiences and did not find reliable differences in the captured fluctuations or experiences with completing the ESM assesments.[74] Nevertheless, further research should investigate which magnitude of fluctuations can be perceived as clinically important by people with advanced cancer. For instance, by using a within-person anchor approach.[75]

While this dissertation found that participants did not perceive the study as having influenced how they felt or what they did during the ESM period (Chapter 6), it remains possible that such effects occurred without their awareness. For example, such effects could include changes in symptom levels due to increased attention to the symptoms, which could also induce greater negative affect and further aggravate symptom levels. Notably, increased awareness of certain experiences could also be beneficial to the patient, as it could empower them to take a more active role in their healthcare, thereby potentially improving symptom levels.[76] Additionally, participants could avoid activities that would interfere with completing ESM assessments, thereby changing their behavior due to participation in the study.[77] Therefore, in order to better understand such participation

effects, it is essential for future research to investigate whether and how patients' symptom, well-being, and activity levels, and their attention to and awareness thereof change over the course of ESM participation and in the long-term. Recently, a taxonomy of participation effects in ESM research was put forward, offering guidance on how such effects could be assessed.[77] Encouragingly, in the context of cancer, Bootsma et al. did not find increases in fatigue levels over three weeks of using ESM.[36] Although our own data in Chapter 5 and 6 would have allowed us to examine such changes, this was not the focus of our analyses and should be addressed in future research.[4,5]

As an important step in the later stages of ESM use in oncology, researchers should evaluate whether ESM has led to tangible new insights that directly impact clinical practice to better support patients' symptoms, thoughts, behaviors, and well-being. While ESM holds strong theoretical promise, its practical value must be demonstrated through measurable contributions to improving clinical decision-making, symptom management, or other relevant patient outcomes. Demonstrating such impact is essential for justifying further investment in ESM as a research and clinical tool, especially in a healthcare landscape where multiple competing interventions and services aim to improve patient care.

Implications for practice and policy

The importance of considering complex dynamics of symptoms and well-being

Findings of Chapters 5 to 7 showed that symptoms and well-being often fluctuate considerably and that the patterns of these fluctuations differ between persons. These findings underscore that, to improve the support for patients' symptoms or well-being, healthcare professionals should consider the timing of when patients feel better or worse and which personal determinants might drive such fluctuations. This underscores the importance of existing guidelines for the management of symptoms that require taking the personal determinants into account, such as cancer-related fatigue.[78] In Chapters 5 and 6, we indeed observed that tiredness was the strongest fluctuating symptom, begging the question of what drives these fast and individual-specific fluctuations. Considering the temporality and personal determinants of patients' problems may improve the effectiveness of symptom management by providing both the healthcare professional and the patient with more approaches to tackle the problem(s). Moreover, explicitly reflecting on the dynamics and determinants of symptoms with the patient could strengthen patients' self-management (an outcome that is often improved by self-monitoring; Chapter 2).[1,79] Apart from using ESM or other diary methods, healthcare professionals can take these factors into account by asking open-ended questions to identify moments when patients felt better or worse and which factors they think influence their symptoms and well-being.

ESM can provide a "deep dive" into patients' problems

Findings of Chapters 2 and 5 to 8 showed that ESM is a promising method for structurally gathering detailed knowledge into the unique needs of people with advanced cancer.[1,4–7] ESM not only captures the time specificity of symptoms, thoughts, behaviors, and well-being, but also provides valuable insight into potentially important contextual factors such as activities, food intake, or sleep quality. In clinical practice, such monitoring could supplement existing tools in oncology such as traditional PROMs to provide a "deep dive" into patients' problems.

Logically, an ESM tool seems most relevant for patients with symptoms that are expected to fluctuate during and across days, where retrospective PROMs or clinical assessments fail to provide insights. Chapter 6 shows that symptoms often have stronger fluctuations during and across days when on average moderate to severe levels are reported across the period.[5] This means that the use of ESM is likely most insightful for monitoring people with at least moderate severity of chronic problems, such as chronic pain or cancer-related fatigue. In some cases, fine-grained insights could provide an additional handle to tackle these problems that may otherwise be hard to treat.[24,68,80] For instance, using less-intensive routine PROMs, such as during follow-up in patients with advanced cancer, can detect a symptom or problem that is hard to treat, where the use of more intensive ESM assessments could then provide additional informative insights for treating the problem. Yet, in some cases, patients with problems that are at low severity levels may also benefit from gaining insights with ESM. For instance, to determine what leads to rare occurrences of disrupted sleep or episodes of anxiety or dyspnea.

So how can healthcare professionals begin using ESM? As smartphones become increasingly integrated into daily life, digital ESM tools are more accessible than ever and will likely only become more accessible. However, pen and paper ESM alternatives can still provide a valuable start for monitoring patients' problems in case digital systems are not yet in place. Instructing patients to keep a diary and monitor the same symptoms, contexts and other important factors at key time points in the day can provide insight into the time specificity and (with some data processing) into possible associated factors of key symptoms. Regardless of the format, the assessment schedule should be tailored to what the patient is willing to use and should not ask more of the patient than what is required to gain a good understanding of the problem at hand.

Another important question regarding the future use of ESM in oncology practice is whether it could serve as a stand-alone self-monitoring tool. According to healthcare professionals in Chapter 8, some individuals with advanced cancer value having a structured way of monitoring their symptoms and well-being.[7] Moreover, healthcare professionals expected

that such monitoring could improve self-insight and potentially support self-management.[7] Yet, Chapter 8 also showed that using ESM for self-monitoring comes with two major pitfalls.[7] First, not all patients will be capable of interpreting feedback graphs independently. Second, the confrontation with the decline of their own symptoms, well-being, or overall health status could induce great distress in patients. For this reason, healthcare professionals suggested that feedback should always be discussed in the presence of a clinician.[7] Providing patients with the opportunity to discuss feedback with their clinician can help patients deal with the feedback and increase the acquisition of personal insights.[36] While ESM-based self-monitoring may offer patients valuable and actionable insights, future evaluations must carefully weigh the potential benefits against these risks.

Successful PROM endeavors can precede and guide the implementation of ESM in practice

The practical barriers perceived by healthcare professionals in Chapter 8 highlight that implementing ESM tools in oncology will require substantial support and structured guidance.[7] Encouragingly, implementation processes can be aligned with those from previous successful implementation endeavors of routine PROMs into clinical practice (Chapter 8).[7,58,59] At the meso level, leadership and governance of hospitals or cancer centers play a vital role in creating a supportive infrastructure and facilitating integration into existing workflows. This includes providing healthcare professionals the flexibility to allocate time for the discussion of patients' needs from the ESM reports or to answer clinician alerts (Chapter 8).[7] Positively, according to healthcare professionals interviewed in Chapter 8, specific tasks related to ESM use can be delegated to designated staff.[7] For instance, in the CHEMO-SUPPORT intervention, nurses were tasked with completing a symptom checklist that incorporates PROM responses during patient consultations.[57,81] At UZ Brussel, given their close contact with the patient and their central role in the multidisciplinary team, onco-coaches appear well-positioned to work with ESM and refer patients to the right healthcare professionals. However, some of the healthcare professionals in Chapter 8, including the onco-coaches, were quite skeptical of the added value of self-report measures in general.[7] While training and education is already seen as vital for implementing symptom monitoring tools in practice,[58,59] it could also tackle the apparent skepticism of healthcare professionals by providing insight into the evidence of the effectiveness of such tools (Chapter 8).[7]

One way to integrate ESM into practice could be by slowly integrating it into a successfully implemented PROM system. Starting with an existing PROM infrastructure may offer several benefits. For instance, some of the healthcare professionals interviewed in Chapter

8 expressed enthusiasm about the benefits of routine self-report systems, particularly their potential to improve healthcare provision.[7] In many clinical scenarios, regular routine PROMs would be less resource and time-intensive for both patients and healthcare professionals than ESM. Yet, they could be equally effective for improving aspects of care, such as improving communication between the patient and healthcare professional and the automated detection of needs. Additionally, the successful implementation of PROMs and the firsthand experience of their effectiveness may serve to increase healthcare professionals' openness to more advanced self-monitoring tools like ESM. As there is large functional overlap in PROM and ESM systems, ESM systems could then be further developed from the PROM systems that are in place. In this way, ESM can be integrated as a type of in-the-moment high-frequency PROMs in the same system, seamlessly integrated into the same digital system. This would reduce the need for additional platforms or programs (e.g., "not yet another program to open in a consultation", Chapter 8),[7] making ESM more accessible in everyday clinical workflows. In these endeavors, technical support of IT services for healthcare professionals will be key to ensure a smooth operating of the system to keep its users motivated.[57]

General conclusion

This dissertation adapted ESM for use by people with advanced breast and lung cancer and evaluated its potential for both research and practice. Adaptation was achieved by gaining a comprehensive overview of how the methods had been used in oncology before and by successfully developing and content-validating the ESM-AC questionnaire, aimed at capturing symptoms, well-being and daily contexts of people with advanced cancer in daily life. This dissertation provides important evidence for the potential of high-intensity ESM as a research tool to obtain temporally fine-grained knowledge of patients' problems. Participants showed good adherence and reported low burden, and the method revealed dynamic fluctuations in symptoms and well-being that remained undetected by traditional retrospective PROMs. This dissertation also showed that ESM has the potential to support clinical care. By offering clinicians a more nuanced picture of patients' problems and by allowing timely intervention through the addition of clinical alarms and automated feedback, ESM could complement existing assessment approaches and contribute to more personalized oncology care. However, not all patients may be willing or able to engage with ESM, and its effective implementation calls for careful methodological design. Further research should focus on determining when and for whom ESM is most beneficial, how it can be efficiently integrated into clinical workflows, and what level of intensity balances insight with sustainability.

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List of abbreviations

COSMIN = Consensus-Based Standards for the Selection of Health Measurement Instruments;

EMA = Ecological Momentary Assessment;

EORTC = European Organization for Research and Treatment of Cancer;

EORTC QLQ-C30 = European Organization for Research and Treatment of Cancer Core Quality of Life Questionnaire;

ESM = Experience Sampling Methods;

ESM-AC questionnaire = Experience Sampling Methods for People Living With Advanced Cancer questionnaire;

FACIT-Pal = Functional Assessment of Chronic Illness Therapy – Palliative Care;

FWO = Fonds Wetenschappelijk Onderzoek;

IPOS = Integrated Palliative Care Outcome Scale;

PROM = Patient-Reported Outcome Measure;

VAS = Visual Analogue Scale

Curriculum Vitae

Joran Geeraerts holds a master's degree in Psychology : Theory and Research (2020, KU Leuven). During his full-time internship from 2019 to 2020 at the Research Group of Quantitative Psychology and Individual Differences (KU Leuven), he investigated data quality in the context of experience sampling methods, exploring statistical and methodological techniques to detect careless responding. From November 2020 to December 2025, he worked as a doctoral researcher at the End-of-Life Care Research Group at the Vrije Universiteit Brussel (VUB). His work mainly focused on adapting experience sampling methods to study the symptoms and well-being of people with advanced cancer in daily life.

ACADEMIC PUBLICATIONS

Geeraerts, J., Pivodic, L., Nooijer, K. D., Rosquin, L., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2025). The potential of experience sampling methods in palliative care. *Palliative Medicine*, *39*(2), 307-317. [2024 SCIE impact factor 3.9; Ranking Q1; ranking 31/185 HEALTH CARE SCIENCES & SERVICES]

Geeraerts, J., Pivodic, L., Rosquin, L., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2024). Uncovering the daily experiences of people living with advanced cancer using an experience sampling method questionnaire: development, content validation, and optimization study. *JMIR Cancer*, *10*(1), e57510. [2023 SCIE impact factor 3.3; Ranking Q2; ranking 118/322 ONCOLOGY]

Geeraerts, J., de Nooijer, K., Pivodic, L., De Ridder, M., & Van den Block, L. (2024). Intensive longitudinal methods among adults with breast or lung cancer: scoping review. *Journal of Medical Internet Research*, *26*, e50224. [2022 SCIE impact factor 7.4; Ranking D1; ranking 3/106 HEALTH CARE SCIENCES & SERVICES]

Atefi, G., Viechtbauer, W., Czaja, S., van Knippenberg, R. J., Van den Block, L., **Geeraerts, J.**, ... & Bartels, S. L. (2025). Momentary appraisals of uncontrollable and unpredictable events predict caregiver well-being: Evidence from an experience sampling study. *Journal of Contextual Behavioral Science*, *36*, 100889. [2024 SCIE impact factor 3.0; Ranking Q1; ranking 41/185 PSYCHOLOGY, CLINICAL]

Geeraerts, J., Pivodic, L., De Nooijer, K., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2024). Investigating experiences of people with advanced breast or lung cancer in their natural context: protocol for an experience sampling study. *BMJ Open*,

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Geeraerts, J., Pivodic, L., de Nooijer, K., Rosquin, L., Decoster, L. Fontaine, C., Joris, S., Crombez, G., Naert, E., De Ridder, M., Van den Block, L. (*accepted at Palliative Medicine, 2025*) Uncovering Fluctuations in Daily Symptoms and Well-being Among People with Advanced Cancer: An Experience Sampling Methods Study [2024 SCIE impact factor 3.9; Ranking Q1; ranking 31/185 HEALTH CARE SCIENCES & SERVICES]

Geeraerts, J., de Nooijer, K., Pivodic, L., Crombez, G., Decoster, L. Fontaine, C., Joris, S., Naert, E., De Ridder, M., Van den Block, L. (*submitted at Supportive Care in Cancer, 2025*) A Comparison of In-The-Moment and Retrospective Patient-Reported Outcome Measures in Advanced Cancer [2024 SCIE impact factor 3.0; Ranking Q1; ranking 17/173 REHABILITATION]

Geeraerts, J., de Nooijer, K., Pivodic, L., Decoster, L. Fontaine, C., Joris, S., Naert, E., Crombez, G., De Ridder, M., Van den Block, L. (*submitted at European Journal of Cancer Care*) Oncology Healthcare Professionals' Perspectives on the Clinical Utility of Experience Sampling Methods

Vogelsmeier, L. V., Siepe, B. S., Ulitzsch, E., Eisele, G., **Geeraerts, J.**, Klocek, A., ... & Fried, E. I. (2025). Identifying careless responding in ecological momentary assessment: Inconsistent signals from different detection methods in the WARN-D data. (PREPRINT)

ACADEMIC AWARDS

Palliative Medicine's Editor's Choice of March 2025 for *'The potential of experience sampling methods in palliative care. (2025)'*

ACADEMIC PRESENTATIONS

2025

'Experience Sampling Methods to Uncover Symptom and Wellbeing Fluctuations of People With Advanced Cancer in Daily Life'. 19th World Congress of the European Association for Palliative Care, Helsinki, Finland. Oral presentation.

'Comparing In-the-Moment and 7-Day Recall Assessments of Symptoms and Wellbeing in Advanced Breast and Lung Cancer'. Society for Ambulatory Assessments Conference, Leuven, Belgium. Oral presentation.

2024

'Using Experience Sampling Methods to Uncover Within- and Between Person Variability of Symptoms, Concerns, and Wellbeing'. Oncology Research Center Day, Brussels, Belgium. Oral presentation.

'Feasibility and Acceptability of Experience Sampling Methods in Cancer Research: A Pilot Study.' 13th World Research Congress of the European Association for Palliative Care, Barcelona, Spain. Poster presentation.

'Exploratie van geheugeneffecten bij symptoomrapportage door mensen met gevorderde borst- of longkanker'. Expertisenetwerk Palliative Zorg-dag, Brussels, Belgium. Oral presentation.

2023

'Detecting Careless Responding in Experience Sampling Studies'. Society for Ambulatory Assessments Conference, Amsterdam, the Netherlands. Oral presentation.

'Electronic Daily Intensive Longitudinal Methods among Adults with Breast or Lung Cancer: A Scoping Review'. Society for Ambulatory Assessments Conference, Amsterdam, the Netherlands. Oral presentation.

'Digital Self-Report Monitoring in Oncology: the Use of Intensive Longitudinal Methods among People with Advanced Breast or Lung Cancer'. End-of-Life Care research group public seminar, Brussels, Belgium. Oral presentation.

2020

'Investigating Careless Responding Detection Techniques in Experience Sampling Methods (ESM)'. Annual Meeting of the Belgian Association of Psychological Sciences, online. Virtual poster presentation.

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SUPPLEMENTARY MATERIALS

Given the size of the supplementary materials, only the ESM-AC questionnaire is attached to this dissertation. All other supplementary materials can be digitally accessed via https://osf.io/v7ube/.

Supplementary Materials of Chapter 5

Supplementary Material 1. The Experience Sampling in Advanced Cancer Questionnaire (ESM-AC)

Assessment schedule	Subdomain	Item	Response options
Momentary	Physical symptoms	1. At this moment, I have pain.	Slider: 0 = Not at all, 100 = Very much
		1'. If pain > 10: The pain is located at these body parts.	Multiple-choice: ○ Head ○ Back ○ Hands or fingers ○ Stomach ○ Hips ○ Knees ○ Feet or toes ○ Other body parts
		2. At this moment, I feel tired.	Slider: 0 = Not at all, 100 = Very much
		3. At this moment, I feel nauseated.	Slider: 0 = Not at all, 100 = Very much
		4. At this moment, I'm experiencing breathing problems (shortness of breath, difficulty breathing).	Slider: 0 = Not at all, 100 = Very much
	Negative affect	5. At this moment, I feel restless.	Slider: 0 = Not at all, 100 = Very much
		6. At this moment, I feel sad.	Slider: 0 = Not at all, 100 = Very much
	Positive affect	7. At this moment, I feel content.	Slider: 0 = Not at all, 100 = Very much
		8. At this moment, I feel relaxed.	Slider: 0 = Not at all, 100 = Very much
		9. At this moment, I feel energized.	Slider: 0 = Not at all, 100 = Very much
	Cognitive complaints	10. Since last beep, I had trouble concentrating on things like reading a newspaper, watching	Slider: 0 = Not at all, 100 = Very much

Assessment schedule	Subdomain	Item	Response options
		television or following a conversation.	
	Psychological well-being	11. At this moment, I feel worried.	Slider: 0 = Not at all, 100 = Very much
		12. At this moment, I feel down.	Slider: 0 = Not at all, 100 = Very much
		13. At this moment, I feel anxious.	Slider: 0 = Not at all, 100 = Very much
	Social well-being	14. At this moment, I feel lonely.	Slider: 0 = Not at all, 100 = Very much
	Global well-being	15. At this moment, I feel …	Slider: 0 = Very bad, 100 = Very good
		16. If there is anything else you want to note about the period since last beep, you can do it here:	Open question
	Social company	17. Who was with me at the moment of the beep?	Multiple-choice: ○ Partner ○ Child(ren) ○ Other family members ○ Friend(s) ○ Acquaintance(s) ○ Healthcare provider ○ Co-worker(s) ○ Online contact (like Whatsapp) or phone call ○ Others ○ Nobody (I am alone)
	Social company (Appraisal)	*18a. If not 'Nobody (I am alone)':* I think this company is pleasant.	Slider: 0 = Not at all, 100 = Very much
		18b. If 'Nobody (I am alone)': It feels okay to be alone.	Slider: 0 = Not at all, 100 = Very much

Assessment schedule	Subdomain	Item	Response options
	Location	19. Where was I at the moment of the beep?	Multiple-choice: ○ At home ○ At someone else's home ○ Store ○ Hospital ○ Work ○ Outside ○ Somewhere else
	Location (Appraisal)	20. I'm content with the place I was at.	Slider: 0 = Not at all, 100 = Very much
	Location (Bed/Couch)	*21. If 'At home', 'At someone else's home', or 'Hospital':* I was in bed or on the couch when the beep went off.	Yes-No
	Activity	22. What was I doing at the moment of the beep?	Multiple-choice: ○ Active leisure (walking, cycling, odd jobs, …) ○ Passive leisure (watching tv, internet, something quiet, …) ○ Work ○ Households, groceries, home administration ○ En route (e.g., on the bus) ○ Self-care, personal hygiene (washing, dressing, …) ○ Eating, drinking ○ Taking care of my (grand)child ○ Conversation, interaction ○ Sleeping ○ Nothing ○ Something else
	Activity (Appraisal)	*23. If not 'Nothing':* I liked the activity I was	Slider: 0 = Not at all, 100 = Very much

Assessment schedule	Subdomain	Item	Response options
		doing right before the beep.	
		24. If not 'Nothing': I felt limited doing the activity right before the beep.	Slider: 0 = Not at all, 100 = Very much
	Medication	25. Since last beep, I have used the following substance(s):	Multiple-choice: ○ Medication ○ Cigarettes ○ Alcohol ○ Caffeine (e.g., coffee) ○ Nothing ○ Other substances
		25'. If 'Medication': I used medication against:	Multiple-choice: ○ Pain ○ Nausea ○ Anxiety or restlessness ○ Others
	Meta (disturbance)	26. I thought it was disturbing to fill in this questionnaire	Slider: 0 = Not at all, 100 = Very much
	Meta (difficulty)	27. It was difficult for me to complete this questionnaire.	Slider: 0 = Not at all, 100 = Very much
	Meta (attention)	28. I completed the questions attentively.	Slider: 0 = Not at all, 100 = Very much
Morning	Sleep quality	29. This night, I slept well.	Slider: 0 = Not at all, 100 = Very much
		29'. If sleep > 10: I think I slept less well, because:	Open question
Evening	Physical functioning	30. Today, due to my physical condition, I had difficulty performing my daily activities.	Slider: 0 = Not at all, 100 = Very much
	Psychological well-being	31. I feel like I was able to enjoy my day today.	Slider: 0 = Not at all, 100 = Very much

Assessment schedule	Subdomain	Item	Response options
	Social well-being	32. Today I received the support I needed from my loved one(s).	Slider: 0 = Not at all, 100 = Very much
		33. Today I felt like I was a burden to my loved one(s).	Slider: 0 = Not at all, 100 = Very much
	Spiritual-Existential well-being	34. Today I felt hopeful.	Slider: 0 = Not at all, 100 = Very much
	Meta (non-response)	35. Today I deliberately did not respond to a beep.	Yes-No
	Meta (non-response)	35'. *If 'yes':* I did not respond to that beep because:	Multiple-choice: ○ I could not react (on time) ○ I was sleeping or resting ○ I did not feel like it ○ I was too stressed ○ The questionnaire would take me too much time ○ I experienced the beep as burdensome ○ Other

Note. All phrasings are English forward translations of the original Dutch questionnaire. Questionnaire development is discussed in detail in Geeraerts, J., Pivodic, L., Rosquin, L., Naert, E., Crombez, G., De Ridder, M., & Van den Block, L. (2024). Uncovering the daily experiences of people living with advanced cancer using an experience sampling method questionnaire: development, content validation, and optimization study. *JMIR Cancer*, *10*(1), e57510. https://doi.org/10.2196/57510